

8-2012

Community participation group interventions for children and adolescents with neurodevelopmental disabilities : A systematic review ; and, Community participation for girls and women living with Rett syndrome

Jaimi Andrews
Edith Cowan University

Follow this and additional works at: https://ro.ecu.edu.au/theses_hons



Part of the [Medicine and Health Sciences Commons](#)

Recommended Citation

Andrews, J. (2012). *Community participation group interventions for children and adolescents with neurodevelopmental disabilities : A systematic review ; and, Community participation for girls and women living with Rett syndrome*. https://ro.ecu.edu.au/theses_hons/45

This Thesis is posted at Research Online.
https://ro.ecu.edu.au/theses_hons/45

2012

Community participation group interventions for children and adolescents with neurodevelopmental disabilities : A systematic review ; and, Community participation for girls and women living with Rett syndrome

Jaimi Andrews
Edith Cowan University

Recommended Citation

Andrews, J. (2012). *Community participation group interventions for children and adolescents with neurodevelopmental disabilities : A systematic review ; and, Community participation for girls and women living with Rett syndrome*. Retrieved from http://ro.ecu.edu.au/theses_hons/45

This Thesis is posted at Research Online.
http://ro.ecu.edu.au/theses_hons/45

Edith Cowan University

Copyright Warning

You may print or download ONE copy of this document for the purpose of your own research or study.

The University does not authorize you to copy, communicate or otherwise make available electronically to any other person any copyright material contained on this site.

You are reminded of the following:

- Copyright owners are entitled to take legal action against persons who infringe their copyright.
- A reproduction of material that is protected by copyright may be a copyright infringement.
- A court may impose penalties and award damages in relation to offences and infringements relating to copyright material. Higher penalties may apply, and higher damages may be awarded, for offences and infringements involving the conversion of material into digital or electronic form.

**Community participation group interventions for children
and adolescents with neurodevelopmental disabilities: A
systematic review.**

And

**Community participation for girls and women living with
Rett syndrome.**

Jaimi Andrews

Use of Thesis

This copy is the property of Edith Cowan University. However the literary rights of the author must also be respected. If any passage from this thesis is quoted or closely paraphrased in a paper or written work prepared by the user, the source of the passage must be acknowledged in the work. If the user desires to publish a paper or written work containing passages copied or closely paraphrased from this thesis, which passages would in total constitute an infringing copy for the purpose of the Copyright Act, he or she must first obtain the written permission of the author to do so.

Signed.....

Dated.....

COPYRIGHT AND ACCESS DECLARATION

I certify that this thesis does not, to the best of my knowledge and belief:

(i) Incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education;

(ii) Contain any material previously published or written by another person except where due reference is made in the text; or

(iii) Contain any defamatory material

Signed.....

Dated.....

Community participation for girls and women living with Rett syndrome

Jaimi Andrews

**A report submitted in Partial Fulfilment of the Requirements of the Award of Bachelor of
Occupational Therapy Honours, Faculty of Health and Science, Edith Cowan University**

Submitted August 2012

I declare that this written assignment is my own work and does not include:

- i. Material from published sources used with proper acknowledgement; or
- ii. Material copied from the work of other students

Signature: _____.

Date: _____.

DECLARATION

I certify that this literature review and research project does not incorporate, without acknowledgement, any material previously submitted for a degree or diploma in any institution of higher education and that, to the best of my knowledge and belief, it does not contain any material previously published or written by another person except where due reference is made in the text.

Signature.....

Date.....

Acknowledgements

This review and research project would not have been possible without the ongoing support from the Telethon Institute for Child Health Research and Edith Cowan University. In particular, I would like to thank, Dr Sonya Girdler from Edith Cowan University, for her guidance, patience and understanding. The children and families involved in the Australian Rett Syndrome Study should also be acknowledged for their time and dedication in continuing to answer questionnaires. A special thanks to Ms Katherine Bathgate, Dr Jenny Downs and Clinical A/Prof Helen Leonard from the Telethon Institute for Child Health Research for their endless encouragements and contributions. This thesis is dedicated to my wonderful parents who have supported me throughout my life and given me the opportunity to attend university and complete my honours degree.

Table of Contents

Literature Review.....	1-30
Abstract.....	3
Background.....	4
Methods	6
Results	8
Discussion.....	14
References.....	18
Appendices	21
Journal guidelines for authors.....	25
 Research Report	 31-64
Abstract.....	32
Introduction.....	33
Methods	35
Results	39
Discussion.....	44
Conclusion	48
References.....	50
Table of results	53
Journal guidelines for authors.....	58

Literature Review

Community participation group interventions for children and adolescents with
neurodevelopmental disabilities: A systematic review

Jaimi Andrews

AUTHOR'S NOTE

I would like to make note that although my systematic review is primarily based on community participation interventions for girls and women with Rett syndrome, due to limited research available, I will be considering other neurodevelopmental intellectual disabilities such as cerebral palsy, Down syndrome, and Autism Spectrum Disorder.

Community participation group interventions for children and adolescents with neurodevelopmental disabilities: A systematic review

Abstract

Objective: To describe the effectiveness of community integration interventions on community participation, self-esteem and quality of life for children and adolescents with a neurodevelopmental intellectual disability.

Method: Electronic searches of five databases and manual searches of reference lists were conducted. Community integration interventions which targeted friendship development, recreation participation, quality of life and self-esteem were included.

Results: Thirteen studies were included in this review. A variety of study designs and interventions were used. Following interventions, all but one study reported significantly increased friendships, five reported increased recreation participation and one reported increased quality of life and self-esteem. Methodological quality of the studies ranged from adequate to strong.

Conclusions: Community integration interventions appear to be effective in supporting the successful inclusion of children and adolescents with neurodevelopmental intellectual disabilities. Future interventions should consider the impact of several factors, such as impairment, personal and environmental factors, in facilitating community participation.

Key words: Neurodevelopmental intellectual disability · Recreation program · Friendship group · Children · Adolescents · Community participation · Quality of life

Author: Jaimi Andrews

Supervisors: Dr Sonya Girdler and Ms Katherine Bathgate

May 2012

Background

The prevalence of neurodevelopmental intellectual disability in Western Australia is 14.3 per 1000 people (Leonard, Petterson, Bower, & Sanders, 2003). Neurodevelopmental disability refers to a condition or disorder which begins in the early stages of development (conception, birth, infancy, and childhood) (Patel & Merrick, 2011). It can result in mild to profound intellectual disability, behavioural problems, impaired speech, social withdrawal and poor gross motor functioning (Dahan-Oliel, Shikako-Thomas, & Majnemer, 2012). Types of neurodevelopmental disabilities include Rett syndrome, autism, cerebral palsy, Down syndrome, Asperger's syndrome, and Fragile X syndrome. Due to the nature of these disabilities, they can often have a major influence on daily life (Patel & Merrick, 2011). A clear example of this includes limited ability to participate in community activities such as recreation and friendships (Patel & Merrick, 2011).

For children and adolescents with intellectual disabilities, community participation has the ability to enhance physical and mental wellbeing, promote social inclusion, increase self-worth and improve independence (Laugeson, Frankel, Mogil, & Dillon, 2009; Specht, King, Brown, & Foris, 2002). In addition, participation in recreational activities and friendships can increase overall life satisfaction and contribute to one's quality of life (Budruk & Phillips, 2011; Geisthardt, Brotherson, & Cook, 2002; Specht et al., 2002). Although the importance of community participation has been identified, current research suggests that people living with an intellectual disability will participate in less recreational activities than their peers (Law et al., 2006).

To encourage participation in the community, appropriate interventions and programs need to be developed. To date, very few community participation interventions have been identified for children and adolescents with intellectual disabilities. Instead, there has been a focus on the child's health needs such as medical care (Dahan-Oliel et al., 2012). However, interventions and programs which target recreational participation and friendships are reported to be more valued by the families of children with an intellectual disability than interventions focusing on health care

(Dahan-Oliel et al., 2012). Community participation programs have the ability to increase sports participation and social interaction between children with and without disabilities, and improve academic performance and functional skills (Shukla, Kennedy, & Cushing, 1999; Werts, Caldwell, & Wolery, 1996). In addition, interventions provide typically developing children with an opportunity to gain an understanding about disability (Carter et al., 2004; Schleien, Krotee, Mustonen, Kelterborn, & Schermer, 1987).

When designing a community participation intervention for children and adolescents with a neurodevelopmental intellectual disability, several factors should be considered. The International Classification of Functioning, Disability and Health (ICF) is a holistic, theoretical framework which is often used to describe the relationship between activity and participation, and impairment, personal and environmental factors (World Health Organization [WHO], 2005). Impairment factors which may impact the effectiveness of community participation interventions include cognitive and language ability (Kasari et al., 2005) and severity of intellectual disability (Murphy & Carbone, 2008; Shikaka-Thomas, Majnemer, Law, & Law, 2008). Current literature suggests that young people with a more severe intellectual disability are less likely to participate in community activities (Dusseljee, Rijken, Cardol, Curfs, & Groenewegen, 2011; Majnemer et al., 2008). Clinical symptoms also have the ability to impact the frequency and intensity at which a child can participate in recreational activities and friendships (King et al., 2003; Oates, Bebbington, Bourke, Girdler, & Leonard, 2011).

Personal factors which may impact on engagement in programs targeting community participation include age and gender (Kasari et al., 2005). Depending on the age of the child or adolescent, activity preference and availability of leisure activities may vary. It has been suggested that as the child matures, activity preference will change and activities will become less available (Dusseljee et al., 2011). Gender may also influence participation as research suggests that males

prefer more physical activities, whilst girls prefer sedentary activities (Lorenzi, Horvat, & Pellegrini, 2000).

Environmental factors which may influence participation in community interventions include accessibility, family social demographics, and community support (Becker & Dusing, 2010; Kasari et al., 2005; Murphy & Carbone, 2008). It is important to ensure that the environment is accessible for children and adolescents with intellectual disabilities to allow them to participate successfully. Family social demographics such as socio-economic status can affect a child's ability to attend interventions due to the cost of specialised equipment (Murphy & Carbone, 2008). Family needs should also be considered as they may have other children or prior commitments (Fennick & Royle, 2003). Negative and discriminatory attitudes of the community can also inhibit children with an intellectual disability seeking out community participation programs (Law, Petrenchik, King, & Hurley, 2007).

Therefore, the objective of this systematic review is to describe the effectiveness of community integration interventions on community participation, self-esteem and quality of life for children and adolescent's with neurodevelopmental intellectual disabilities.

Methods

Search strategy

A search of the COCHRANE database failed to identify a previous review addressing this objective. Four electronic databases were then searched for this review. Each database was searched from its earliest electronic record (Cumulative Index of Nursing and Allied Health Literature – CINAHL from 1982, MEDLINE from 1966, PsycINFO from 1685, and SPORTDiscus from 1381) until April 2012. The main search terms were grouped into four concepts. The first concept had the following key words with intervention and program added to the end: community-based, friendship,

social skills, group, and peer support. The second concept included Rett syndrome, Down syndrome, autism* (autism, autism spectrum disorder), cerebral palsy, neurodevelopmental disability, intellectual disability and mental retardation. The third concept included outcome key words including community participation, activity participation, friend* (friendship, friends), leisure, recreation, social interaction, interpersonal, self-esteem and quality of life. The fourth concept included children, adolescent, teenager and young. With assistance from the librarian, all terms were adjusted, exploded and truncated in order to match the database being searched. Forward citation searching using the electronic database, Web of Science, was completed on included articles. Manual searches were conducted on all reference lists of retrieved studies however conference proceedings and grey literature were not searched.

Inclusion and exclusion criteria

A priori criteria for inclusion of studies were applied initially to titles and abstracts and then full text articles if the abstract did not provide sufficient information. Studies were included if the community integration intervention was delivered in a group and was aimed at targeting community participation, self-esteem and/or quality of life. Interventions were also not limited to being administered by a specific health profession or discipline. Participants in the studies were restricted to children and adolescents aged five to 18 years with a neurodevelopmental disorder resulting in intellectual disability such as Rett syndrome, Down syndrome, cerebral palsy and autism. For the remainder of this review, neurodevelopmental intellectual disability will be referred to as intellectual disability. Studies were excluded if the interventions were delivered individually or were primarily targeted at parents. Participants which had an acquired neurodevelopmental disability or physical disability were also excluded for this review. Quantitative, qualitative and mixed-method studies were included. Studies reported in any other languages beside English were excluded.

Assessment of methodological quality

Two reviewers independently assessed the quality of each study using the *Standard Quality Assessment Criteria for Evaluating Primary Research Papers* developed by Kmet and colleagues (2004). This quality assessment form contains a 14-item quantitative checklist. Guidelines and instructions have been provided to assist the reviewers to answer the questions and calculate a final score. The reviewers used a scoring system to determine the quality of the paper, which could be described as strong (score of >80%), good (70-80%), adequate (50-70%) or limited (<50%) (Lee, Packer, Tang, & Girdler, 2008). Any discrepancies found between reviewers were resolved through discussion.

Data extraction

Data was independently extracted from selected studies using the following headings: study objective, study design, subject and sample size, intervention used, data collection method, outcome measures, results, discussion and limitations. Once data was extracted, the level of evidence was determined on the National Health and Medical Research Council guidelines (National Health and Medical Research Council [NHMRC], 1999).

Results

Search strategy and selection criteria

Electronic searches located a total of 396 articles using the key terms (*see* Figure 1). The titles and abstracts were reviewed and 325 articles were found not to meet the inclusion criteria and 13 articles were unable to be obtained. The full-text of the remaining 58 articles were reviewed and nine were found to meet inclusion criteria. Reference lists and citations from web of science were

manually searched which identified a further four studies for inclusion. Overall 13 studies were included in this systematic literature review.

An overview of the included 13 articles is presented in Table 1. Study designs included: four randomised control trial's (RCT) (Drysdale, Casey, & Porter-Armstrong, 2008; Frankel et al., 2010; Kasari, Rotheram-Fuller, Locke, & Gulsrud, 2012; Laugeson et al., 2009), one, one-way repeated measures design (Siperstein, Glick, & Parker, 2009), seven quasi-experimental designs (time series, multiple baseline, pre-test-posttest) (Barry et al., 2003; Carter et al., 2004; Fennick & Royle, 2003; Haring & Breen, 1992; MacKay, Knött, & Dunlop, 2007; Schleien et al., 1987; Schleien, Mustonen, & Rynders, 1995), and one mixed methods study (Becker & Dusing, 2010). Within the 13 articles, a variety of interventions were reported. Three were described as recreation programs (Fennick & Royle, 2003; Schleien et al., 1987; Siperstein et al., 2009), two were friendship clubs/groups (Carter et al., 2004; Haring & Breen, 1992), two were community art programs (Becker & Dusing, 2010; Schleien et al., 1995), two were social skills groups (Barry et al., 2003; MacKay et al., 2007), two were friendship training groups (Frankel et al., 2010; Laugeson et al., 2009), one was a PEER-mediated group (Kasari et al., 2012) and one was a community skills group (Drysdale et al., 2008). Overall, 468 young people participated in these interventions: 214 were young people with Autism Spectrum Disorder including Autism and Asperger's syndrome (Barry et al., 2003; Carter et al., 2004; Drysdale et al., 2008; Fennick & Royle, 2003; Frankel et al., 2010; Haring & Breen, 1992; Kasari et al., 2012; Laugeson et al., 2009; MacKay et al., 2007; Schleien et al., 1987; Schleien et al., 1995), one with Down syndrome (Becker & Dusing, 2010), 62 with a non-specified intellectual disability (Drysdale et al., 2008; Haring & Breen, 1992; Siperstein et al., 2009) and 191 were typically developing peers (Barry et al., 2003; Becker & Dusing, 2010; Haring & Breen, 1992; Kasari et al., 2012; Schleien et al., 1987; Schleien et al., 1995; Siperstein et al., 2009). All but one study (Drysdale et al., 2008), reported on friendships, five reported on recreational and activity participation (Becker & Dusing, 2010; Fennick & Royle, 2003; Schleien et al., 1987; Schleien et al.,

1995; Siperstein et al., 2009), five reported on social skills (Barry et al., 2003; Haring & Breen, 1992; Kasari et al., 2012; Laugeson et al., 2009; MacKay et al., 2007), and one reported on quality of life and self-esteem/confidence (Becker & Dusing, 2010).

Quality of studies

The methodological quality of selected studies is presented in Table 1. Overall, methodological quality of the 13 included studies ranged from adequate to strong. There appeared to be no relationship between the type of intervention protocol and the quality of the research. For most articles, the study design, objective, method of subject selection, subject/comparison characteristics and outcome measures were clearly described. Random allocation of subjects and blinding of investigators varied, depending on the study design. Due to the nature of the interventions, it was impossible to blind subjects. Very few articles reported effect sizes, confounding variables or the variance of outcome measures. Other shortcomings included poorly reported sample sizes and assessors were therefore left to make their own conclusions. Generally, the analytical methods were justified appropriately and the results and conclusion sections were reported in detail.

Interventions

The intention of this review was to examine research which reported on various types of community participation interventions, however, the majority of the interventions targeted friendships rather than recreational and leisure interventions. Even though it has been reported that both friendship and leisure participation is important in promoting quality of life and health and well-being for children with intellectual disabilities (Potvin, Prelock, & Snider, 2008), only four of the 13 studies incorporated both friendship facilitation and recreational participation into their programs (Carter et al., 2004; Fennick & Royle, 2003; Schleien et al., 1987; Siperstein et al., 2009).

Of the 13 included articles, seven were specifically designed to target friendship facilitation (Barry et al., 2003; Carter et al., 2004; Frankel et al., 2010; Haring & Breen, 1992; Kasari et al., 2012; Laugeson et al., 2009; MacKay et al., 2007). The aim of these interventions was to develop friendships, teach appropriate social skills for friendship development (conversation and initiation skills), and promote inclusion in peer groups. Three studies (Fennick & Royle, 2003; Schleien et al., 1987; Siperstein et al., 2009) used a recreational program to promote recreational participation in well-known sports and preferred activities, and also encourage friendship development. Finally, two studies (Becker & Dusing, 2010; Schleien et al., 1995) were described as community art programs. These aimed to enhance basic art skills, encourage friendship development and promote participation in art activities such as dancing, singing, acting, and arts and crafts.

The settings of the interventions included two in a school classroom (after-hours) (Frankel et al., 2010; Laugeson et al., 2009), two during recess and lunch at school (Haring & Breen, 1992; Kasari et al., 2012), six in a community setting (leisure centre, museum, performing arts centre, university campus) (Barry et al., 2003; Becker & Dusing, 2010; Fennick & Royle, 2003; Schleien et al., 1987; Schleien et al., 1995; Siperstein et al., 2009) and three in both a classroom and community setting (Carter et al., 2004; Drysdale et al., 2008; MacKay et al., 2007).

Comparison groups varied for all four RCT's. The two friendship training groups (Frankel et al., 2010; Laugeson et al., 2009) were evaluated against 12-week delayed treatment group. The PEER mediated group (Kasari et al., 2012) was compared against a no-treatment group. Lastly, the community skills programme (Drysdale et al., 2008) evaluated the difference between three groups: classroom training, classroom training and community outings, and a no-treatment group.

Outcomes

Four broad outcomes (friendships, recreational participation, quality of life and self-esteem) were evaluated for this systematic literature review (*see* Table 1).

Friendships

Despite using a variety of outcomes measures, all but one study reported significant changes in friendships following interventions. Friendships interventions were evaluated in three RCT studies (Frankel et al., 2010; Kasari et al., 2012; Laugeson et al., 2009), with two (Frankel et al., 2010; Laugeson et al., 2009) using a delayed treatment group, and one (Kasari et al., 2012) with a no-treatment group. Significant improvements in quality and quantity of friendships and play dates were found using a variety of friendship measures including friendship quality scale (Laugeson et al., 2009), quality of play questionnaire (Frankel et al., 2010; Laugeson et al., 2009), social network survey and observations/ interviews (Kasari et al., 2012). A significant decrease in loneliness was also reported using social inclusion scales including the loneliness scale, peers self-concept scale and the pupil evaluation inventory (Frankel et al., 2010). Three of four pretest-posttest studies (Barry et al., 2003; Carter et al., 2004; Fennick & Royle, 2003; Schleien et al., 1987) evaluating friendship interventions reported significant increases in quality, quantity and interaction of friendships. This may have resulted from the reliance on observations to assess friendships (Fennick & Royle, 2003), whilst the other three studies used observations as well as informal interviews and formal social inclusion measures (attitude acceptance scale (Schleien et al., 1987), social support scale, and loneliness scale (Barry et al., 2003). A significant increase in positive friendships and interactions outside of school was reported following the intervention period in two multiple baseline designs (Haring & Breen, 1992; Schleien et al., 1995), one time series design (MacKay et al., 2007), one repeated measures design (Siperstein et al., 2009) and one mixed methods study (Becker & Dusing, 2010). In these studies, friendships were measured using observations (Becker

& Dusing, 2010; Haring & Breen, 1992; Schleien et al., 1995), informal interviews (MacKay et al., 2007), and the peer hang-out-with and friendship inventory (Siperstein et al., 2009).

Recreational participation

Participation in recreational activities was examined in five studies (Becker & Dusing, 2010; Fennick & Royle, 2003; Schleien et al., 1987; Schleien et al., 1995; Siperstein et al., 2009). Two pretest-posttest designs reported a significant increase in sports participation using observations as an outcome measure following a recreational program (Fennick & Royle, 2003; Schleien et al., 1987). Although these two studies reported a significant improvement in recreational participation, only one was assessed as having a strong methodological quality, questioning the strength of the findings (Fennick & Royle, 2003). One repeated measures design (Siperstein et al., 2009) and mixed methods study (Becker & Dusing, 2010) also yielded similar results to the pretest-posttest studies using the adapted sports skills assessment (Siperstein et al., 2009) as well as observations (Becker & Dusing, 2010). In addition, Siperstein and colleagues (2009) found a strong relationship between sports skills and building friendships ($p = 0.01$) and Becker and colleagues (2010) reported that following the recreational intervention, a young girl with Down syndrome had increased motivation to attend other community programs. Another study also reported a significant change in activity participation in informal activities following a friendship club, even though its initial aim was to promote friendships (Carter et al., 2004).

Community participation skills

A three-armed RCT study aimed at evaluating the effectiveness of a community skills intervention (Drysdale et al., 2008) reported a highly significant difference ($p = 0.007$) between the two intervention groups and the control group in shopping skills. Although shopping skills increased for both intervention groups, no significant difference was found between the classroom only intervention group and the classroom and community intervention group for the shopping task. The

methodological quality of the study was found to be strong due to the large sample size and random allocation of young people to groups.

Quality of life and self-esteem

Only one study reported significant improvements in quality of life and self-esteem (Becker & Dusing, 2010). The Pediatric Quality of Life Inventory (PedsQL), a reliable and valid measure (Varni, Seid, & Kurtin, 2001), was used to measure quality of life whilst subject and parent feedback were used to measure self-esteem. However, the adequate methodological quality of the study may limit the ability for the findings to be generalised. The effect size could not be calculated for this study as the total number of subjects was not specified.

Discussion

This systematic review found adequate to strong evidence that community integration interventions appear to be effective in promoting the inclusion of children and adolescents with an intellectual disability.

Findings from this review have highlighted that there are potentially many ways to continue to improve the effectiveness of community participation interventions. Several studies which reported that interventions were delivered in an integrated setting with typically developing peers as well as children with intellectual disabilities were more beneficial than interventions which included only children with intellectual disabilities. Participation in community activities with typically developing peers was important for children with intellectual disabilities as it enhanced normalisation, increased recreational opportunities and encouraged positive friendships (Becker & Dusing, 2010; Carter et al., 2004; Fennick & Royle, 2003; Haring & Breen, 1992; Kasari et al., 2012; Schleien et al., 1987; Siperstein et al., 2009). In studies which only involved children and adolescents with intellectual disabilities (Barry et al., 2003; Carter et al., 2004; Frankel et al., 2010;

Laugeson et al., 2009), it was noted by observers and parents that future programs should include typically developing peers.

Controversy exists in relation to the most appropriate setting for community participation interventions. While some research has found that skills learnt in the classroom were transferred to the playground and not the community (Kasari et al., 2012), other research reported that skills learnt in both the classroom and community, were generalised to the community setting (Carter et al., 2004; MacKay et al., 2007). In comparison, Drysdale and colleagues (2008) found no difference between the classroom setting and the community setting in relation to skill transfer. However the results from this study should be interpreted with caution as only two community outings were undertaken and the study had a small sample size ($n = 12$). Therefore further research is needed.

Another important finding was the importance of considering children activity preference within the programs. Three studies identified that it was important to consider activity preferences of children and adolescents with intellectual disabilities as it significantly increased positive participation in recreational activities (Carter et al., 2004; Fennick & Royle, 2003; Schleien et al., 1987).

In relation to the ICF, several factors which may impact community participation interventions were identified. For impairment factors, clinical symptoms and severity of disability were discussed. Fennick and colleagues (2003) reported that limitations in the ability to communicate significantly impacted on a young persons ability to form friendships. A number of studies also reported that children and adolescents with a more severe intellectual disability, were less likely to recognise friendships (Kasari et al., 2012; MacKay et al., 2007), improve community living skills (Drysdale et al., 2008) or participate in the program as a whole (Siperstein et al., 2009).

Both age and gender emerged as personal factors which could potentially impact on participation in programs. Four studies (Laugeson et al., 2009; MacKay et al., 2007; Schleien et al., 1987; Siperstein et al., 2009) purposefully formed similar age and sex groups to facilitate similar

age and sex friendships. In one study (Siperstein et al., 2009), an older group of children were excluded from the recreational program as it was felt that older children would have different recreational preferences compared to those younger.

Potential environmental factors which could impact participation in community programs for young people with intellectual disability included family social demographics, accessibility, and social support from the community. Several strategies, surrounding family social demographics, were offered to increase participation and attendance in the program including incentives such as paid parking and cost effective programs (Laugeson et al., 2009; MacKay et al., 2007; Siperstein et al., 2009). Other strategies included grouping children based on the parents' and children's availability, prior commitments and geographic location (Fennick & Royle, 2003; MacKay et al., 2007). Several interventions utilised environmental modifications tailored to the young person's needs including assistive equipment and modifications of sports to encourage positive friendships between children with and without intellectual disabilities (Becker & Dusing, 2010; Carter et al., 2004; Fennick & Royle, 2003; Laugeson et al., 2009; MacKay et al., 2007; Schleien et al., 1987; Schleien et al., 1995). Four studies considered community support as an important factor, therefore teachers and typically developing peers learnt strategies to encourage community awareness and promote community inclusion for children with intellectual disabilities (Barry et al., 2003; Fennick & Royle, 2003; Kasari et al., 2012; Schleien et al., 1995).

Limitations of this systematic review should be clarified. Firstly, only four electronic databases were used to search the literature. However, these databases were those most likely to identify research examining the objective of this review. Secondly, very few studies (Drysedale et al., 2008; Frankel et al., 2010; Siperstein et al., 2009) reported effect sizes, making it difficult to compare the relative effectiveness of the individual interventions. Thirdly, parent proxy report was used in several studies of young people with moderate to severe disabilities. This could potentially affect the findings from these studies as it may be difficult for parents to accurately report on their

child's quality of life. Finally, assessment of the methodological quality revealed that four studies (Becker & Dusing, 2010; Carter et al., 2004; Fennick & Royle, 2003; Haring & Breen, 1992) were of adequate quality. This points to the need for more robust methodologies in this area of research.

Overall, this systematic literature review highlights the need to develop and evaluate more interventions which aim to increase leisure participation, friendships, quality of life and self-esteem of young people with intellectual disability. When planning interventions, impairment, personal and environmental factors should be considered. Programs should also aim to be flexible, promote activity preference, encourage active participation and provide enjoyment for all young people (Becker & Dusing, 2010; Murphy & Carbone, 2008). Only 13 articles met the inclusion criteria for this systematic review, indicating that further research is required in this area. The findings from this systematic review will encourage health professionals to facilitate and advocate for the development of community participation interventions for children and adolescents with intellectual disabilities.

References

- Barry, T. D., Grofer-Klinger, L., Lee, J. M., Palardy, N., Gilmore, T., & Bodin, S. D. (2003). Examining the effectiveness of an outpatient clinic-based social skills group for high-functioning children with autism. *Journal of Autism and Developmental Disorders*, 33(6), 685-701. doi: 10.1023/B:JADD.0000006004.86556.e0
- Becker, E., & Dusing, S. (2010). Participation is possible: A case report of integration into a community performing arts program. *Physiotherapy Theory and Practice*, 26(4), 275-280.
- Budruk, M., & Phillips, R. (2011). Quality of life community indicators for parks, recreation and tourism management. London: Springer.
- Carter, C., Meckes, L., Pritchard, L., Swensen, S., Wittman, P. P., & Velde, B. (2004). The friendship club: An after-school program for children with Asperger syndrome. *Family & Community Health*, 27(2), 143-150.
- Dahan-Oliel, N., Shikako-Thomas, K., & Majnemer, A. (2012). Quality of life and leisure participation in children with neurodevelopmental disabilities: A thematic analysis of the literature. *Quality of Life Research*, 21(3), 427-439. doi: 10.1007/s11136-011-0063-9
- Drysdale, J., Casey, J., & Porter-Armstrong, A. (2008). Effectiveness of training on the community skills of children with intellectual disabilities. *Scandinavian Journal of Occupational Therapy*, 15(4), 247-255.
- Dusseljee, J. C. E., Rijken, P. M., Cardol, M., Curfs, L. M. G., & Groenewegen, P. P. (2011). Participation in daytime activities among people with mild or moderate intellectual disability. *Journal of Intellectual Disability Research*, 55(1), 4-18.
- Fennick, E., & Royle, J. (2003). Community inclusion for children and youth with developmental disabilities. *Focus on Autism and Other Developmental Disabilities*, 18(1), 20-27.
- Frankel, F., Myatt, R., Sugar, C., Whitham, C., Gorospe, C. M., & Laugeson, E. (2010). A randomized controlled study of parent-assisted children's friendship training with children having autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 40(7), 827-842. doi: 10.1007/s10803-009-0932-z
- Geisthardt, C. L., Brotherson, M. J., & Cook, C. C. (2002). Friendships of children with disabilities in the home environment. *Education & Training in Mental Retardation & Developmental Disabilities*, 37(3), 235-252.
- Haring, T. G., & Breen, C. G. (1992). A peer-mediated social network intervention to enhance the social integration of persons with moderate and severe disabilities. *Journal of Applied Behavior Analysis*, 25(2), 319-333.
- Kasari, C., Freeman, S., Paparella, T., Wong, C., Kwon, S., & Gulsrud, A. (2005). Early intervention in autism: Focus on core deficits. *Clinical Neuropsychiatry*, 2, 380-388.
- Kasari, C., Rotheram-Fuller, E., Locke, J., & Gulsrud, A. (2012). Making the connection: Randomized controlled trial of social skills at school for children with autism spectrum

- disorders. *Journal of Child Psychology and Psychiatry*, 53(4), 431-439. doi: 10.1111/j.1469-7610.2011.02493.x
- King, G., Law, M., King, S., Rosenbaum, P., Kertoy, M. K., & Young, N. L. (2003). A conceptual model of the factors affecting the recreational and leisure participation of children with disabilities. *Physical & Occupational Therapy in Pediatrics*, 23(1), 63-90.
- Kmet, L., Lee, R., & Cook, L. (2004). Standard quality assessment criteria for evaluating primary research papers for a variety of fields, from <http://www.ahfmr.ab.ca/download.php/>
- Laugeson, E. A., Frankel, F., Mogil, C., & Dillon, A. R. (2009). Parent-assisted social skills training to improve friendships in teens with autism spectrum disorders. *Journal of Autism & Developmental Disorders*, 39(4), 596-606.
- Law, M., Gillian, K., King, S., Kertoy, M., Hurley, P., Rosenbaum, P., . . . Hanna, S. (2006). Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Developmental Medicine & Child Neurology*, 48, 337-342.
- Law, M., Petrenchik, T., King, G., & Hurley, P. (2007). Perceived environmental barriers to recreational, community, and school participation for children and youth with physical disabilities. *Archives of Physical Medicine and Rehabilitation*, 88(12), 1636-1642.
- Lee, L., Packer, T. L., Tang, S. H., & Girdler, S. (2008). Self-management education programs for age-related macular degeneration: A systematic review. *Australasian Journal of Ageing*, 27(4), 170-176.
- Leonard, H., Petterson, B., Bower, C., & Sanders, R. (2003). Prevalence of intellectual disability in Western Australia. *Paediatric and Perinatal Epidemiology*, 17(1), 58-67. doi: 10.1046/j.1365-3016.2003.00469.x
- Lorenzi, D. G., Horvat, M., & Pellegrini, A. D. (2000). Physical activity of children with and without mental retardation in inclusive recess settings. *Education and Training in Developmental Disabilities*, 35, 160-167.
- MacKay, T., Knott, F., & Dunlop, A.-W. (2007). Developing social interaction and understanding in individuals with autism spectrum disorder: A groupwork intervention. *Journal of Intellectual and Developmental Disability*, 32(4), 279-290. doi: 10.1080/13668250701689280
- Majnemer, A., Shevell, M., Law, M., Birnbaum, R., Chilingaryan, G., Rosenbaum, P., & Poulin, C. (2008). Participation and enjoyment of leisure activities in school-aged children with cerebral palsy. *Developmental Medicine & Child Neurology*, 50(10), 751-758.
- Murphy, N. A., & Carbone, P. S. (2008). Promoting the participation of children with disabilities in sports, recreation and physical activities. *American Academy of Pediatrics*, 121(5), 1057-1061.
- National Health and Medical Research Council [NHMRC]. (1999). A guide to the development, implementation and evaluation of clinical practice guidelines. Canberra, ACT: NHMRC.

- Oates, A., Bebbington, A., Bourke, J., Girdler, S., & Leonard, H. (2011). Leisure participation for school-aged children with Down syndrome. *Disability & Rehabilitation*, 33(19/20), 1880-1889.
- Patel, D. R., & Merrick, J. (2011). Chapter 1: Neurodevelopmental disabilities: Introduction and epidemiology. In D. R. Patel, D. E. Greydanus, H. A. Omar & J. Merrick (Eds.), *Neurodevelopmental disabilities: Clinical care for children and young adults* (pp. 1-13). London: Springer.
- Potvin, M. C., Prelock, P. A., & Snider, L. (2008). Collaborating to support meaningful participation in recreational activities of children with autism spectrum disorder. *Topics in language disorders* 28(4), 365-374.
- Schleien, S., Krotee, M., Mustonen, T., Kelterborn, B., & Schermer, A. (1987). The effect of integrating children with autism into a physical activity and recreation setting. *Therapeutic Recreation Journal*, 21(4), 52-62.
- Schleien, S. J., Mustonen, T., & Rynders, J. E. (1995). Participation of children with autism and nondisabled peers in a cooperatively structured community art program. *Journal of Autism & Developmental Disorders*, 25(4), 397-413.
- Shikaka-Thomas, K., Majnemer, A., Law, M., & Law, L. (2008). Determinants of participation in leisure activities for children and youth with cerebral palsy: Systematic review. *Physical & Occupational Therapy in Pediatrics*, 28, 155-169.
- Shukla, S., Kennedy, C. H., & Cushing, L. S. (1999). Intermediate school students with severe disabilities: Supporting their social participation in general education classrooms. *Journal of Positive Behavior Interventions*, 1, 130-140.
- Siperstein, G. N., Glick, G. C., & Parker, R. C. (2009). Social inclusion of children with intellectual disabilities in a recreational setting. *American Association of Intellectual and Developmental Disabilities*, 47(2), 97-107.
- Specht, J., King, G., Brown, E., & Foris, C. (2002). The importance of leisure in the lives of persons with congenital physical disabilities. *American Journal of Occupational Therapy*, 56(4), 436-445.
- Varni, J. W., Seid, M., & Kurtin, P. S. (2001). The PedsQL 4.0: Reliability and validity of the pediatric quality of life inventory version 4.0 generic core scales in healthy and patient populations. *Medical Care*, 39, 800-812.
- Werts, M. G., Caldwell, N. K., & Wolery, M. (1996). Peer modelling of response chains: Observational learning by students with disabilities. *Journal of Applied Behavior Analysis*, 29, 53-66.
- World Health Organization [WHO]. (2005). *International classification of functioning, disability and health*. Geneva, Switzerland: Author.

Figure 1 Flow chart of study selection

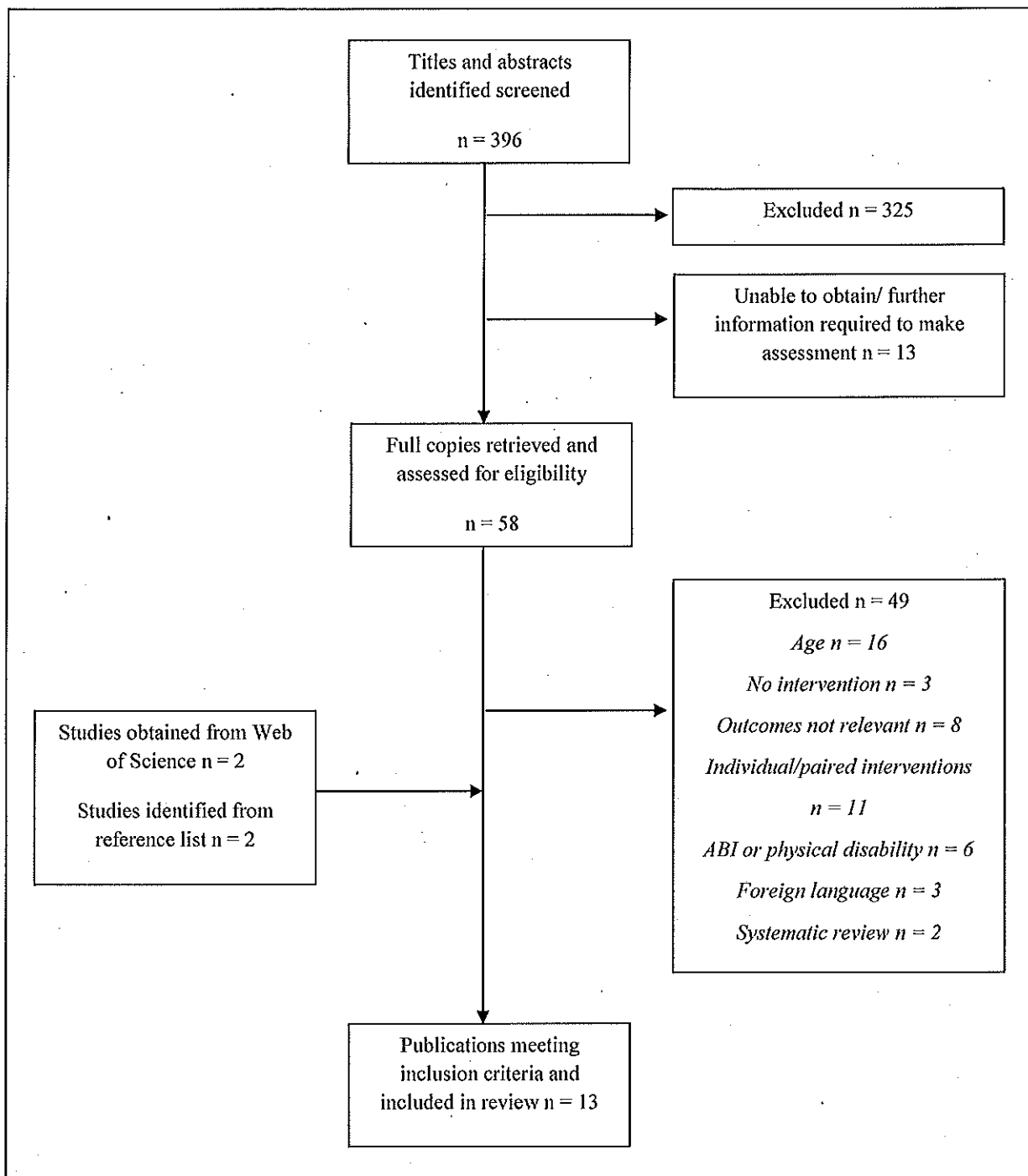


Table 1: Findings of the included studies

Author, year, country	Design/ number of subjects	Subjects	Intervention group	Control group	Outcome measures	Results	* Methodological quality
Frankel 2010 USA	RCT (n = 68)	Children with high functioning ASD and their parents 7-11y	Children's friendship training group (n = 35) Aim: develop friendships 12 weekly sessions Classroom (after-hours) Children and parents (separated)	Delayed intervention group (n = 33)	Friendships <ul style="list-style-type: none"> The loneliness scale (child) Piers self-concept scale (child) Quality of play questionnaire (parent) The Pupil Evaluation Inventory (teacher) Social skills <ul style="list-style-type: none"> Social Skills Rating System (parent) 	Friendships Significant change ($p > 0.05$) ↑ in play dates (number, behaviour), child's self-control and assertiveness Significant change ($p < 0.025$) ↓ loneliness, ↑ popularity	<i>Strong quality</i> (score = 24/28) Investigators and subjects not blinded. Large sample size, analytical and variance described, random allocation, study design evident, and results/conclusion sufficiently reported
Mackay 2007 UK	Quasi-experimental time series (n = 46)	Children with high functioning ASD 6-16y	Social skills group Aim: friendship skills 12-16 weekly sessions 8 per group 6 groups: 3 x 6-11yo; 3 x 12-16yo Classroom (after-hours) & community outings	-	Friendships <ul style="list-style-type: none"> Informal interviews (parent) Social skills <ul style="list-style-type: none"> Spence social skills and social competence with peers questionnaires (parent/child) The three things – key social skills (parent) 	Friendships ↑ social participation and appropriate conversation ($p = 0.001$) Social skills ↑ social skills and competence (turn-taking, personal space, body language) ($p = 0.01$)	<i>Good quality</i> (score = 20/26). Sample size and confounding variables partially reported. Investigators blinded, no random allocation and variance not reported. Random allocation, and results/conclusion sufficiently reported
Laugeson 2008 USA	RCT (n = 33)	Teenagers with ASD 13-17y	Parent assisted social skills group (n = 17) Aim: develop friendships 12 weekly sessions 7 per group Classroom (after hours) Children and parents (separated)	Delayed intervention group (n = 16)	Friendship <ul style="list-style-type: none"> Friendship quality scale The quality of play questionnaire (parent/teen) Social skills <ul style="list-style-type: none"> Social skills training scale (parent/teacher) Test of adolescent social skills knowledge (teen) 	Friendships <ul style="list-style-type: none"> ↑ hosted get togethers, better quality friendships ($p = 0.05$) Social skills <ul style="list-style-type: none"> ↑ knowledge of social skills compared to delayed intervention group ($p = 0.05$) 	<i>Good quality</i> (score = 20/28). Investigators and subjects not blinded, variance not reported, sample size and confounding variables partially reported. Random allocation, and results/conclusion sufficiently reported.
Kasari 2012 USA	RCT (n = 75)	Children with high functioning ASD (n = 30) Typically developing peers (n = 45) 6-11y	Peer mediated group (n = 60) Aim: develop friendships 2 sessions/wk for 6 wks Recess and lunch at school	No intervention Children with high functioning ASD (n = 15)	Friendships <ul style="list-style-type: none"> Social network survey (child) Playground observations (assessor) Self, peer and teacher reports Social skills <ul style="list-style-type: none"> Teachers report 	Friendships <ul style="list-style-type: none"> ↑ no. Friendships and social network ($p = 0.02$) Reciprocal friendships were nonsignificant ↓ isolation on the playground Social skills <ul style="list-style-type: none"> ↑ social skills ($p = 0.01$) 	<i>Good quality</i> (score = 21/28). Blinding of subjects not reported, sample size and confounding variables partially reported. Investigators blinded, random allocation, and results/conclusion sufficiently reported.
Becker 2010 USA	Mixed methods (n = not stated)	Girl with Down syndrome (11y, mild cognitive impairment) Typically developing	Performing arts group Aim: participation in dance, voice, acting 14 weekly sessions Community performing arts	-	Quality of life <ul style="list-style-type: none"> PedsQL (parent) Friendships, Self-confidence, Engagement <ul style="list-style-type: none"> Observations 	<ul style="list-style-type: none"> ↑ interaction and engagement with peers, ↑ QOL and self-confidence ↑ motivation for other community programs 	<i>Adequate quality</i> (score = 9/14). Poorly described study. Study design and subject selection not clearly identified. Blinding, random allocation, analytical

		children (8-14y)	centre		• Parent report		methods and variance N/A.
Haring 1992 USA	Multiple baseline (n = 11)	Adolescent's with autism (n = 1) & intellectual disability (n = 1) Typically developing peers (n = 9) 12-13y	Social network group Aim: facilitate social interaction and inclusion Weekly sessions 2 Groups: 1 (n = 5), 2 (n = 6) Recess, lunch and classroom (after-hours)	-	Social interaction/ friendships • Observations (assessor) • Qualitative - satisfaction, peer interaction/ relationship (child and peers)	Friendships • ↑ friendships (quality, quantity, interactions) • ↑ peer interaction outside of school and continued peer network Social skills • ↑ knowledge of social skills	<i>Adequate quality</i> (score = 15/22). Sample size not identified. Confounding variables, variance and analytical methods partially described. Blinding and random allocation N/A.
Barry 2003 USA	One-group pretest-posttest (n = 11)	Children with high functioning autism (n = 4) Typically developing peers (n = 7) (only used for assessment period) 6-9y	Social skills group Aim: Social skills and friendships 8 weekly sessions Out-patient university psychology clinic (community)	-	Social skills • SSRS- social skills competence (parent) • Social skills observations – play (investigators) • Social skills interview – was the child using the skills in community setting (parent) Friendship/Social Support • Social support scale (child) • Loneliness scale (child)	Social Skills • Significant ↑ Greeting skills (p = 0.03) & conversation skills (p = 0.10) • ↑ Greeting skills outside clinic Friendships/Social Support • Significant ↑ in perceived social support from peers (p = 0.05), play (p = 0.03) • ↑ meaningful peer relationships between children with and without autism • ↓ perceived loneliness	<i>Good quality</i> (score = 18/24) Small sample size, confounding variables not considered, and study design not clearly identified. Investigators blinded, results/conclusion sufficiently reported, and analytical methods justified.
Siperstein 2009 USA	One-way repeated measures (n = 67)	Children with mild intellectual disability (n = 29) Typically developing peers (n = 38) 8-13yo	Summer recreational program Aim: participation in swimming, basketball, soccer, free play, arts & crafts 5 sessions/wk for 4 wks 12 per group Leisure centre	-	Friendships • Peer hang-out-with and friendship inventory (child) Recreational participation • Adapted sports skills assessment (investigators)	Friendships • Children with ID made new friends and more accepted by peers Recreational participation • Significant ↑ in swimming and soccer skills for children with ID (p = 0.001) • Strong relationship between sports skills and building relationships (p = 0.01)	<i>Good quality</i> (score = 17/22) Blinding and random allocation N/A. Study design, confounding variable and variance not clearly identified. Large sample size and analytical methods described.
Drysdale 2008 Ireland	RCT (n = 40)	Children with moderate intellectual disability (8 autism and 32 non- specified) 9-11yo	Community skills group Aim: participation in games, learning shopping and telephone skills 2 sessions/wk for 8 wks 6 per group 2 groups: 1 - classroom and community training (n = 12); 2 - classroom training (n = 12) Classroom (after hours) and	No intervention → normal classroom activities (n = 16)	Community skills (shopping and telephone) • Observations • Task analysis	Community skills (shopping and telephone) • ↑ shopping skills for both intervention groups (p = 0.007), no change for control group • No significant difference between intervention groups and control group in handling of money skills or telephone skills	<i>Strong quality</i> (score = 24/28) Subjects not blinded. Confounding variables considered, large sample size analytical methods described, random allocation, blinded investigators, study design evident, and results/conclusion sufficiently reported.

community outings							
Fennick 2003 USA	Two-group pre- test post-test (<i>n</i> = ?)	Children with mild to severe autism (<i>n</i> = 5) Typically developing peers 6-13yo	Recreation group Aim: participation in swimming, gymnastics, develop friendships 2 groups: 1 - swimming (<i>n</i> = 3); 2 - gymnastics (<i>n</i> = 2) Leisure centre	-	Recreational participation/ Friendships • Observations → participation, attendance and enjoyment • Parent survey	Recreational participation • Positive feedback on programs Friendships • No improvement in friendships • ↑ participation in group community programs	<i>Adequate quality</i> (score = 11/20). Random allocation and blinding N/A. Analytical methods, results and conclusion partially described. Small sample size and confounding variables not considered
Schleien 1995 USA	Multiple baseline (<i>n</i> = 32)	Children with mild to severe autism (<i>n</i> = 7) Typically developing peers (<i>n</i> = 25) 7-11yo	Community art program Aim: develop friendships, learn art skills 7 monthly sessions Community museum	-	Friendships • Observations – positive interactions, appropriate and inappropriate behaviour	Friendships • Significant ↑ in positive interactions between children with and without autism (<i>p</i> = 0.05) • No change in initiation or conversation	<i>Strong quality</i> (score = 18/22) Random allocation and blinding N/A. Sample size is large. Confounding variables and variance partially described
Schleien 1987 USA	One-group pretest- posttest (<i>n</i> = 69)	Children with severe autism (<i>n</i> = 2) Typically developing peers (<i>n</i> = 67) 7-12yo	Summer recreation program Aim: participation in badminton, basketball, volleyball, gymnastics, swimming, tennis, squash, free time 5 sessions/wk for 3 wks 3 age groups: 7-8yo; 9- 10yo; 11-12yo University campus (community)	-	Friendships • Attitude acceptance scale (peers) Play/participation • Behavioural observations – in play and with peers (children and peers)	Play/participation • Appropriate play significantly ↑ in recreational activities • ↑ depending of participants preferred activity Friendships • ↑ in appropriate peer interaction	<i>Strong quality</i> (score = 18/22) Random allocation and blinding N/A. Sample size, variance and confounding variables not mentioned. Analytical methods and results/conclusions sufficiently described.
Carter 2004 USA	Two-group pretest- posttest (<i>n</i> = 10)	Children with Asperger's syndrome 8-15yo	Friendship club Aim: develop friendships and skills. 6 weekly sessions 2 age groups: 8-10y (<i>n</i> = 6); 11-15yo (<i>n</i> = 4) Classroom (after hours) and community	-	Friendships, enjoyment, activity participation • Observations • Verbal and written feedback from children and parents	Friendships • Most children had ↑ friendships Activity participation • ↑ activity participation and enjoyment	<i>Adequate quality</i> (score = 13/22). Random allocations and blinding N/A. Study design, outcome measures, analytical methods and results not sufficiently described. Variance and confounding variables not described

* N.B. – Scoring for methodological quality = total sum ('yes'x2 + 'partial'x2) / total possible score (28 – number of N/A x 2)

Guidelines for Contributions by Authors

For literature review only

Journal of Intellectual and Developmental Disability

Guidelines for Contributors

Journal of Intellectual & Developmental Disability

Purpose

The *Journal of Intellectual & Developmental Disability* (JIDD) is the official journal of the *Australasian Society for Intellectual Disability* (ASID). JIDD is an international, multidisciplinary journal in the field of intellectual and developmental disability. The Journal publishes original qualitative and quantitative *Research Articles*, *Literature Reviews*, *Conceptual Papers*, *Policy Analysis Papers*, *Brief Reports*, *Case Reports*, *Data Briefs*, and *Opinions & Perspectives*. JIDD also publishes *Book Reviews* written at the invitation of the Book Review Editor.

Submission

All submissions should be made online at the *Journal of Intellectual & Developmental Disability* Manuscript Central site: <http://mc.manuscriptcentral.com/cjid>. New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre. Authors should prepare and upload two versions of their manuscript. One should be a complete non-anonymous version of the text, while the second should be an anonymous version that has all information identifying the author(s) (including acknowledgements and any source of funding) removed from the files so it can be sent anonymously to referees. When uploading files authors should designate the non-anonymous version as "File not for review" and the anonymous version as "Main Document."

Form

Authors should prepare manuscripts according to the *Publication Manual of the American Psychological Association* (6th ed.). Text should be double-spaced. Instructions for preparing tables, figures and references appear in the *Manual*. All manuscripts (except *Data Briefs* and *Opinions & Perspectives*) must include a Structured Abstract of no more than 150 words typed on a separate page with appropriate subheadings: Background, Method, Results, Conclusions. These should outline the questions investigated, the design, essential findings and main conclusions of the study. A cover sheet should be uploaded separately and must include title, running head (not exceeding 40 characters), author(s), affiliation(s), Author Note (see below under Ethical Standards), and address (including an email address) for correspondence. As manuscripts are reviewed anonymously, the running head (rather than the author's name), should appear as a header on each page and other identifying material should be omitted from the anonymous version of the manuscript.

Length

The suggested maximum length (double-spaced pages) for each type of submission is as follows: *Full-length articles* – 20 pages (including references, tables and figures); *Brief Reports* and *Case Reports* – 8 pages; *Data Briefs* and *Opinions & Perspectives* – 5 pages. Manuscripts exceeding these limits may be accepted depending on the importance and complexity of the content.

Terminology

JIDD uses *people first* language. The general form *person with a disability* is used rather than *disabled person*, so descriptions such as *a boy with Down syndrome* and *adults with spina bifida* are acceptable. As *normal* has multiple meanings, more precise terms such as *children without a hearing impairment* should be used. Generic descriptions such as *students*, *participants*, and *adults* are preferred to the term *subjects*. JIDD uses the term *intellectual disability* rather than *mental retardation* or *learning disability*.

Tables and Illustrations

Professional quality tables and figures should be presented on separate pages and their approximate location in the text indicated. A signed release form must accompany any photographs of people. Care should be taken to conceal the identity of persons in photographs. Images should be submitted as TIF, EPS, PDF, or JPG (preferred) files. Scanned images should be of a sufficient resolution, i.e., 300 dpi for halftones/color, 500 dpi for combination halftones, and 1000–1200 dpi for line art.

Ethical Standards

Authors should disclose in an Author Note (on a separate cover sheet):

- (a) A request that the manuscript be considered for publication.
- (b) A statement that the manuscript has not been published elsewhere, is not currently submitted elsewhere, and is significantly different from other manuscripts that the author has submitted elsewhere.
- (c) A statement that the ethics procedures have been followed and the standards governing research involving human participants in force in the country in which the research has been conducted have been met (note that The Code of Ethics of the World Medical Association [Declaration of Helsinki] represents a minimal requirement).
- (d) The source of all research funding, whether the funding body has imposed any restrictions on free access to or publication of the research data, and authors' financial and non-financial conflicts of interest, such as direct or indirect financial benefit. Please include the subheader, "Conflict of Interest," in the Acknowledgement section at the end of your manuscript. If no such conflict exists, simply respond "None."

Please note that details on ethics procedures and informed consent must also appear in the *Method* section of the paper.

Peer Review

All manuscripts are peer reviewed, with the exception of submissions to *Opinions & Perspectives*. The Editor (or the Associate Editor responsible for a manuscript) selects several reviewers from the JIDD Editorial Panel to review each paper. If appropriate, a guest reviewer with specific expertise

may be consulted. The process is anonymous in that the identity of authors and reviewers is not known to the other party. The Editor (or Associate Editor) then makes the final decision about acceptance for publication. The review process normally takes at least several months—longer when revision is necessary (revisions are often requested).

Data Sharing

Authors of data-based articles in JIDD should have their research data available for at least 5 years after publication. On request, these data should be shared with other competent professionals for reanalysis, solely for the purpose of verifying the published findings, provided that participants' confidentiality is protected and unless legal rights concerning proprietary data prevent their release. Where relevant, the specific computer program used for data analysis should be identified.

Data Briefs

This section contains succinct summaries of significant current data (often national data) on trends in demographics, service provision, expenditure, and other issues. Submissions are subject to peer review. No abstract is required.

Opinions & Perspectives

This section provides a forum for discussion and debate about important current issues, innovations and policy perspectives in the form of short, well-reasoned, clearly written commentaries. No abstract is required. Submissions undergo editorial review (rather than peer review). Detailed editorial comments may not be provided on submissions that are not accepted.

Final Copy and Proofs

A copy of the accepted version of the manuscript should be retained by the author for proofreading purposes. A pdf proof of the copy-edited article will be available to the corresponding author for correction prior to publication.

Submitting a paper to Journal of Intellectual & Developmental Disability

Before preparing your submission, please consult the information below and in JIDD's *Editorial Policy and Notes for Contributors*. This information may also be found via JIDD's website: <http://www.informahealthcare.com/jidd>

All submissions should be made online at the *Journal of Intellectual & Developmental Disability* Manuscript Central site: <http://mc.manuscriptcentral.com/cjid> New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre.

Authors should prepare and upload two versions of their manuscript. One should be a complete (non-anonymous) version of the text, while the second should be an anonymous version that has all information identifying the author(s) removed from the files so it can be sent anonymously to referees. When uploading files authors should designate the non-anonymous version as "File not for review" and the anonymous version as "Main Document."

Papers are accepted for consideration on condition that you will accept and warrant the conditions outlined here. In order to ensure both the widest dissemination and protection of material published in our Journal, we ask authors to assign the rights of copyright in the articles they contribute. This enables Informa UK Ltd to ensure protection against infringement.

1. It is a condition of publication that authors vest or license copyright in their articles, including abstracts, in the *Australasian Society for Intellectual Disability* (ASID). This enables us to ensure full copyright protection and to disseminate the article, and the journal, to the widest possible readership in print and electronic formats as appropriate. Authors may, of course, use the material elsewhere *after* publication providing that prior permission is obtained from Informa UK Ltd. Authors are themselves responsible for obtaining permission to reproduce copyright material from other sources.
2. We shall prepare and publish your Article in the Journal. We reserve the right to make such editorial changes as may be necessary to make the Article suitable for publication; and we reserve the right not to proceed with publication for whatever reason. In such an instance, copyright in the Article will revert to you.
3. You hereby assert your moral rights to be identified as the author of the Article according to the UK Copyright Designs & Patents Act 1988.
4. You warrant that you have secured the necessary written permission from the appropriate copyright owner or authorities for the reproduction in the Article and the Journal of any text, illustration, or other material. You warrant that, apart from any such third party copyright material included in the Article, the Article is your original work, and cannot be construed as plagiarising any other published work, and has not been and will not be published elsewhere.
5. In addition, you warrant that the Article contains no statement that is abusive, defamatory, libelous, obscene, fraudulent, nor in any way infringes the rights of others, nor is in any other way unlawful or in violation of applicable laws.
6. You warrant that, wherever possible and appropriate, any patient, client or participant mentioned in the text has given informed consent to the inclusion of material pertaining to themselves, and that they acknowledge that they cannot be identified via the text.
7. If the Article was prepared jointly with other authors, you warrant that you have been authorised by all coauthors to sign this Agreement on their behalf, and to agree on their behalf the order of names in the publication of the Article.

There are no page charges in the *Journal of Intellectual & Developmental Disability*.

Offprints: Corresponding authors can receive 50 free reprints, free online access to their article through our website (<http://www.informahealthcare.com>) and a complimentary copy of the issue containing their article. Complimentary reprints are available and additional reprints can be ordered when proofs are received. If you have any queries, please contact our reprints department at jenn.kane@informausa.com

Book Reviews: Books for, or offers to, review should be sent to the Book Review Editor: Dr Rachel Mayes, Faculty of Health Sciences, University of Sydney, PO Box 170, Lidcombe, NSW 1825, Australia. E-mail: rachel.mayes@sydney.edu.au

Editorial Office:

Journal of Intellectual & Developmental Disability, Special Education Centre, University of Newcastle, Callaghan,

NSW 2308, Australia.

Editors: Susan Balandin, e-mail: Susan.Balandin@hiMolde.no and Ian Dempsey, e-mail:

Ian.Dempsey@newcastle.edu.au

Editorial Assistant: Genevieve Farrell, e-mail: Genevieve.Farrell@newcastle.edu.au

For more information on our journals and books publishing, visit our website:
<http://www.informahealthcare.com/jidd>

Research Report

Community participation for girls and women living with Rett syndrome.

Jaimi Andrews

Community participation for girls and women living with Rett syndrome

Abstract

Purpose: To describe the relationship between impairment, personal and environmental factors, and community participation for Australian girls and women with Rett syndrome

Methods: Data was collected from the 2009 follow-up questionnaire completed by families participating in the Australian Rett Syndrome Database ($n = 214$). Univariate and multivariate logistic regression were used to analyse relationships between impairment, personal and environmental factors and participation.

Results: In 2009, the mean age was 17.6 years ($SD = 7.95$, range three to 34 years) with 114 (53.3%) girls still at school and 100 (46.7%) women post school. Frequency of activities was influenced by levels of walking, community support and maternal education. For girls living at home, participation in activities was associated with greater functional independence, higher levels of maternal education and better family income. Participation in recreational (90.1%), physical/skill-based (67.6%) and/or social (70.3%) activities were commonly reported by families, whilst self-improvement (17.6%) activities were less reported. Younger girls participated in activities mainly with family members and older girls more frequently participated with carers.

Conclusion: Participation for girls and women with Rett syndrome could be enhanced by stronger community supports. Future studies should use both qualitative and quantitative methodologies to determine the level of satisfaction and enjoyment experienced by girls and women in community activities.

Key words: Rett syndrome · disability · community participation · International Classification of Functioning, Disability and Health

Author: Jaimi Andrews

Supervisors: Dr Sonya Girdler, Ms Katherine Bathgate, Dr Jenny Downs, Clinical A/Prof
Helen Leonard

Submitted: August 2012

Introduction

Rett syndrome is a severe and rare neurodevelopmental disorder which predominantly affects females, with a prevalence of one in 8,600 Australian females aged five to 18 years [1,2]. In most cases, it is associated with an X-linked dominant mutation of the *MECP2* gene [3]. It is characterised by a period of apparently normal physical and intellectual development up until six to 18 months of life at which point the child begins to display signs of stagnation or regression in development [4]; however, some parents have reported that subtle signs of delayed development may appear even earlier [5]. Clinical presentations includes loss of acquired fine and gross motor skills, development of stereotypical hand movements (mouthing, claspings, complex finger movements, hand wringing and tapping) and absence or loss of communication skills. Common comorbidities in Rett syndrome include epilepsy, scoliosis, gastro-intestinal dysfunction, feeding and nutritional problems, and breathing abnormalities [6].

Community participation can be defined as one's ability to interact and engage with others in social or recreational activities outside the home [7]. It is important for individuals with an intellectual disability to have the opportunity to participate in community activities as it can enhance overall physical and psychological wellbeing as well as contribute to their self-worth, self-esteem and quality of life [8-11]. Current research suggests that people living with an intellectual and physical disability participate in fewer recreational activities than their peers [12,13]. This may be the case for those with Rett syndrome because of the complex nature of the disorder.

A range of underlying factors contribute towards a person's ability to participate within the community, especially those with severe intellectual and physical disability. The International

Classification of Functioning, Disability and Health (ICF) is a holistic, theoretical framework which provides a universal classification system to describe health and health-related states of all people [14]. It is used to explore the relationships between body functions and structures (impairment factors), contextual factors (personal and environmental) and activities and participation. The ICF is therefore a useful framework in the investigation of factors influencing the community participation of girls and women with Rett syndrome.

Historically research on children with a disability has focused on impairment factors, and only recently contextual factors have begun to be identified as possible factors affecting community participation [15]. Research involving those with a mild and moderate disability has highlighted how community participation is influenced by impairment, personal and environmental factors [16]. However little is known about the factors that might promote successful community participation for girls and women with Rett syndrome.

Previous research on impairment factors for young people with a mild to moderate intellectual disability suggests that the more severe the intellectual disability, the less the likelihood of participating in community activities [17,18]. Furthermore it has been reported that children with cerebral palsy with poorer gross motor functioning experienced greater restrictions in community participation [19].

Personal factors including functional independence and age have been recognised as influencing community participation. Children with Down syndrome with poorer functional ability were less likely to be part of friendships, sports and hobbies [20]. Mixed findings have been found in relation to age and community participation with some studies suggesting that as children with an intellectual and physical disability grow older, they participate in less

recreational activities and more social activities [12,17]. In contrast, another study found that as younger children with complex communication needs grow, they participate in less recreational, social and self-improvement activities [21].

Research suggests that environmental factors are the most important factors to consider when participating in the community. Families of children with a physical and intellectual disability who have poorer community support and live in a non-metropolitan area experienced increased difficulty in accessing community activities [12,23]. Additionally, children with an intellectual disability were less likely to participate in social and leisure activities if their parents had a lower income or education level, poorer physical and mental health and less available time [20,23].

The purpose of this study was to describe the relationships between impairment and contextual factors and community participation for girls and women with Rett syndrome. The main hypothesis for this study was: Impairment factors (mobility and behaviour), personal factors (age and functional independence) and environmental factors (parent health status, parent socio-economic status, parent available time, community support, place of residence) would influence the community participation for girls and women with Rett syndrome.

Methods

Study design

A cross-sectional design was used to examine the relationship between impairment, personal and environmental factors and community participation.

Participants

Participants for this study were participating in the Australian Rett Syndrome Database (ARSD) which is a population-based study collecting longitudinal data since 1993 [24]. To be included in the database, the girl or woman must have a confirmed diagnosis of Rett syndrome which requires them to have a pathogenic *MECP2* mutation or meet the current diagnostic criteria [25]. Cases can be referred from clinicians and families as well as the Australian Paediatric Surveillance Unit and the Rett Syndrome Association of Australia [1]. At enrolment in the database, clinicians and families receive an initial questionnaire and since 2000, follow-up questionnaires have been distributed to families every two to three years. For this study, data from the 2009 follow-up questionnaire which collected information regarding the individual's current health status and functioning, and current community activities was used. To be included in this study, individuals had to be female, have a confirmed Rett syndrome diagnosis and the 'activities in the community' question had to have been completed in the 2009 follow-up questionnaire.

Ethical considerations

Ethics approval was obtained from Princess Margaret Hospital for Children Ethics Committee (reg. no. 447/EP) and Edith Cowan University, Western Australia. All data is stored at Telethon Institute for Child Health Research according to the approved privacy policy.

Data collection instruments

Identified factors were grouped into impairment factors, personal factors and environmental factors according to the ICF [14]. *Impairment factors* included mobility and behaviour problems. Behaviour problems were measured by the general mood and fear/anxiety

subscales of the Rett Syndrome Behaviour Questionnaire (RSBQ), with a higher score indicating greater behavioural problems [26]. *Personal factors* included child age at the time the questionnaire was returned and level of functional independence as measured by the Functional Independence Measure for Children (WeeFIM) [27]. A higher score on the WeeFIM indicated a higher level of functional ability. *Environmental factors* included community support (measured by the Family Support Scale (FSS)) [28], parent availability of time (measured by the Family Resource Scale (FRS)) [29], accessibility (determined by using the Accessibility/Remoteness Index of Australia (ARIA)) [30], and parental physical and mental health (Short Form Health Survey (SF-12)) [31]. Additionally socio-economic status (determined by maternal education, parental occupation measured by the Australian and New Zealand Standard Classification of Occupations (ANZSCO) [32], and the families ability to save money) was included. Higher scores indicated better community support, more available time, and increased health and wellbeing.

Data coding and analysis

Community participation outcomes included the overall participation in community activities, the variety of activities, the frequency of activities, and who accompanied the girl or woman in the activity. The *overall participation* of activities was grouped into two categories: those who participated in an activity and those who reported no activity participation. Only girls and women living at home were included in this outcome as it was expected that girls living in a group home would participate in at least one activity. The *variety* of community activities was coded into four categories according to the Children's Assessment of Participation and Enjoyment (CAPE) model [33]: recreational activities (e.g., visiting the zoo, going ten pin bowling, leisure groups), physical/skill based activities (e.g. swimming, horse riding, dancing), social activities (e.g. shopping, going to the movies, a concert or restaurant) or self-

improvement activities (e.g. church, holidays, library). Variety was further described as low participation if the young women participated in one to three activities and high participation if they participated in four or more activities. *Frequency* of community activities was scored on a continuous scale based on how many times the young women attended a particular activity per year. An overall frequency was then calculated for each participant by summing the frequencies for all activities. *With whom the girl or women participated* in the activities was coded into two outcomes: with or without a carer and/or with or without a family member.

Participants were divided into four age groups for analysis: early childhood (< 8 years), primary school ($8 \leq 13$), adolescence ($13 \leq$ still at school) and post school. Post school was further classified according to living in the family home or elsewhere (e.g. group home). For the purpose of this study, the ARIA [30] categories: very remote, remote and outer regional areas were combined due to small numbers. Additionally, some maternal education and ANZSCO categories [32] were combined due to small numbers. Mean substitution was used if there was 25% or less missing items in the scale.

Relevant data was cleaned and coded in FileMaker Pro 11 then exported into STATA 11 for statistical analysis. Chi-square tests, one-way analysis of variance (ANOVA) and t-tests were used to describe the relationships between community participation outcomes and categorical (age, mobility, ARIA and SES) and continuous (subscales of the RSBQ, the WeeFIM, the SF-12, parent availability of time, and community support) factor variables. Univariate and multivariate logistic regression was used for analysis of binary community participation outcomes and poisson linear regression was used to examine factors impacting frequency of

community participation. For all environmental factors, with exception of the ARIA, the analysis was restricted to daughters living at home.

Results

Sample characteristics

In 2009, 260 follow-up questionnaires were distributed of which 226 were returned (87% response fraction). Data on the community activities question was provided by 214 families (94.7%) with most families ($n = 182$, 85.0%) reporting that their daughter participated in community activities. Participants had a mean age of 17.6 years ($SD = 7.95$, range 3 to 34 years) with 114 (53.3%) girls still at school and 100 (46.7%) women attending post school options. For girls who were still at school, 26 (12.2%) were <8 years, 42 (19.6%) were $8 \leq 13$ years, and 46 (21.5%) were >13 years. Of women who were post school, 38 (38.0%) lived in a group home and 62 (62.0%) lived with their parents. With regards to mobility, 82 families (38.3%) reported that their daughter had mildly restricted levels of walking, 40 (18.7%) had severely restricted levels of walking, and 92 (43.0%) were either able to support their weight briefly during transfer or required full assistance

The majority (68.7%) of families lived in major cities, 44 (20.6%) lived in inner regional areas, and 23 (10.8%) in outer regional/remote/very remote areas. Forty nine (27.5%) mothers had completed some high school, 42 (23.6%) completed year 12, 46 (25.8%) had a vocational qualification (Tafe or Advanced dip.), and 41 (23.0%) had a university degree. The majority of mothers reported their occupation as homemakers (45.5%) whilst most fathers reported that they were in a manager/professional occupation (41.3%) or clerk/trade occupation (43.2%). Most (78.5%) families provided information about their financial situation with 88 (52.4%) families reporting that they could save some money, eight (4.8%)

reporting that they had some money left over but they just spend it, and 72 (42.9%) reported that they could not save money.

Overall participation in activities

Of the girls and women living at home ($n = 175$), 145 (82.9%) reported participating in an activity and 30 (17.1%) reported participating in no activities. The univariate relationships between the ICF predictor factors and the outcome participation in an activity, are presented in Table I. Girls and women had greater odds of participating in an activity if they had a higher functional independence (OR = 1.05, 95% CI 1.00-1.09, $p = 0.05$), if their mother had a university degree compared to mothers with some high school education (OR = 4.87, 95% CI 1.00-23.71, $p = 0.05$) and if their families were able to save money compared to those who could not save (OR = 4.87, 95% CI 1.00-23.71, $p = 0.07$). The relationship between community participation, and maternal education (OR = 5.23, 95% CI 1.06-25.79, $p = 0.05$) and functional independence (OR = 1.04, 95% CI 1.00-1.09, $p = 0.06$) persisted, even after adjusting for age group. However, the effect of saving money on participation in activities was no longer present after adjusting for the father's occupation (OR = 1.61, 95% CI 0.59-4.36, $p = 0.35$). The girls and women's age, mobility, and behaviour, family factors such as place of residence, level of community support, parent mental and physical health, parent available time, parental occupations and maternal education did not appear to influence activity participation.

Variety of activities

One hundred and sixty four (90.1%) individuals were reported to participate in recreational activities, 123 (67.6%) in physical/skill-based activities, 128 (70.3%) in social activities and

32 (17.6%) in self-improvement activities. The majority of the girls and women participated in four or more recreational (61.0%), physical/skill-based (69.3%), social (73.4%) and self-improvement (93.8%) activities. Engagement in all four types of activities was similar across all age groups. The univariate relationships between variety of activities and the ICF factors; impairment, personal and environmental, are presented in Table II. Girls and women who had more mood related behaviours had less odds (OR = 0.64, 95% CI 0.39-1.06, $p = 0.08$) of participating in self-improvement activities but the effect was reduced after adjustment for age group (OR = 0.71, 95% CI 0.42-1.19, $p = 0.19$). Daughter's whose mothers who had completed year 12 had greater odds (OR=3.33, 95% CI 1.16-9.61, $p = 0.03$) of participating in recreational activities whilst those whose mothers who had completed a university degree had increased odds (OR=2.96, 95% CI 0.88-9.95, $p = 0.08$) of participating in social activities when compared to those whose mothers who had completed some high school. After adjusting for age group, the relationship between maternal education and recreational activities had a greater likelihood (OR=3.48, 95% CI 1.19-10.19, $p = 0.02$) whilst the relationship between maternal education and social activities had a smaller likelihood (OR=2.79, 95% CI 0.82-9.46, $p = 0.10$). Girls and women whose mothers had a clerk/trade qualification had increased likelihood (OR=2.26, 95% CI 0.97-5.24, $p = 0.06$) of participating in recreational activities compared to mothers who were homemakers. This relationship was still present after adjusting for age group (OR=2.21, 95% CI 0.94-5.18, $p = 0.07$). There were few strong relationships for personal characteristics such as age, mobility, functional independence and fear anxiety behaviour and environmental characteristics such as place of residence, community support, financial situation, father occupation, parent mental and physical health and parental availability of time.

Frequency of activities

The average frequency of activity per year was 217.55 (SD = 218.91) which equates to approximately 4.2 times per week. The univariate relationships between frequency of activities and impairment, personal and environmental factors can be seen in Table I. Compared to those who were younger than eight years old, girls who were still at school and aged $8 \leq 13$ (IRR = 0.42, 95% CI 0.26-0.67, $p = 0.00$) and >13 (IRR = 0.52, 95% CI 0.33-0.83, $p = 0.01$) engaged in activities less frequent, and this relationship persisted after separately adjusting for mobility ($8 \leq 13$: IRR = 0.42, 95% CI 0.26-0.68, $p = 0.000$; >13 : IRR = 0.52, 95% CI 0.33-0.82, $p = 0.005$), general mood behaviour ($8 \leq 13$: IRR = 0.38, 95% CI 0.24-0.62, $p = 0.000$; >13 : IRR = 0.48, 95% CI 0.30-0.76, $p = 0.002$), fear anxiety behaviour ($8 \leq 13$: IRR = 0.39, 95% CI 0.25-0.63, $p = 0.000$; >13 : IRR = 0.48, 95% CI 0.31-0.76, $p = 0.002$) and functional independence ($8 \leq 13$: IRR = 0.39, 95% CI 0.24-0.63, $p = 0.000$; >13 : IRR = 0.48, 95% CI 0.30-0.78, $p = 0.003$). For women who had left school, no difference was found in the frequency of activities between those living at home and those living in a group home. On the other hand, girls and women who had severely restricted levels of walking were more likely (IRR = 1.41, 95% CI 0.99-2.02, $p = 0.06$) to frequently participate in activities compared to those who required full assistance when walking. Daughter's whose mothers had a higher education qualification (IRR = 1.75, 95% CI 1.15-2.66, $p = 0.01$) or whose family had greater community support (IRR = 1.22, 95% CI 1.03-1.44, $p = 0.02$) had increased frequency of activities. Even after adjusting separately for age group, mobility (IRR = 1.37, 95% CI 0.96-1.96, $p = 0.08$), maternal education (IRR = 1.69, 95% CI 1.13-2.53, $p = 0.01$) and community support (IRR = 1.19, 95% CI 1.01-1.41, $p = 0.04$) continued to have an effect on how often the girls and women participated. The relationship between community support and the frequency of activities also remained significant after the adjustment of mobility (IRR = 1.22, 95% CI 1.03-1.44, $p = 0.02$). The girls and women's behaviour and functional

independence, as well as environmental factors including place of residence, financial situation, parent occupation, parent mental and physical health and parental availability of time did not have a significant effect on the frequency of activities.

Involvement of family/carer

Overall, 123 (41.8%) cases participated in activities with a carer, 111 (37.76%) participated with family, three (1.0%) with friends, 42 (14.3%) with a carer and family, five (1.7%) with a carer and friends, eight (2.7%) with family and friends and two (0.7%) with family, friends and a carer. Additionally, 136 (54.6%) individuals reported participating with a carer only and 113 (45.4%) reported participating without a carer, whilst 149 (51.4%) individuals participated with family only and 141 (48.6%) participated without family. The univariate relationships between predictor factors of impairment, personal and environmental factors and who the girls and women were accompanied with can be seen in Table III. For all girls and women, it was found that as they aged, they were more likely to participate with a carer ($p < 0.000$) and less likely to participate with family members ($p < 0.002$). Women who had left school and were living in a group home were 3.6 times more likely to participate with a carer in activities than those living at home (OR = 3.62, 95% CI 1.43-9.19, $p = 0.01$) and less likely to participate with family compared to those living at home (OR = 0.32, 95% CI 0.15-0.7, $p = 0.004$). This relationship persisted even after separately adjusting for mobility (with carer: OR = 3.60, 95% CI 1.41-9.16, $p = 0.007$; with family OR = 0.32, 95% CI 0.15-0.70, $p = 0.004$), general mood behaviours (with carer: OR = 3.27, 95% CI 1.26-8.50, $p = 0.02$; with family OR = 0.33, 95% CI 0.15-0.73, $p = 0.006$), fear anxiety behaviours (with carer: OR = 3.62, 95% CI 1.41-9.31, $p = 0.008$; with family OR = 0.33, 95% CI 0.15-0.72, $p = 0.005$) and functional independence (with carer: OR = 3.68, 95% CI 1.44-9.40, $p = 0.007$; with family OR = 0.31, 95% CI 0.14-0.69, $p = 0.004$). Child characteristics such as general mood

behaviour, fear anxiety behaviour, and functional independence and family characteristics such as maternal education, parent mental and physical health, financial situation and place of residence did not predict who was accompanying the girls and women.

Discussion

This study found that age and mobility influenced how often girls and women with Rett syndrome participated in community activities as did the level of maternal education and community support. For girls and women who lived with their parents, greater participation in activities were related to greater functional independence, as well as higher levels of maternal education and better family income. Common activities included social, recreational and/or physical/skill-based activities. Age was related to who the girls participated with for activities, with younger girls participating with family members and older girls participating with carers.

This study found that for girls still at school, younger girls participated more frequently in activities compared to older girls. At a younger age, children are more likely be involved in family activities as families play a vital role in supporting and facilitating community participation. As children grow older, they usually become more aware of their own participation needs [21,34]. However, possibly due to the medical effects of epilepsy [35] and scoliosis [36] during the school years and the physical demands placed on the family, their participation in activities became less frequent. There was also a trend towards women who were post school engaging in more frequent activities most likely due to post school options including structured activity programs.

Our findings on relationships between functional abilities and overall participation in activities were consistent with previous studies of children with intellectual disabilities who were less likely to participate in activities in the presence of greater functional limitations [16,37]. Interestingly, girls and women with more severely restricted levels of walking were more likely to frequently participate in activities compared to those with mildly restricted levels of walking. This may be linked to the use of wheelchairs for mobility during outings [38], and the possibility that girls with less restricted levels were less likely to use wheelchairs and therefore less likely to engage in community outings. As for girls who require full assistance for mobility, those with severely restricted levels of walking may have had access to more supported participation opportunities to meet their needs.

In this study higher levels of community support for families was associated with their daughter's participating in activities more frequently. In general, children and adults with an intellectual disability still remain the most socially excluded people in Australia and continue to experience negative and discriminatory attitudes within their community [39]. However, there is limited literature on the effectiveness of strategies to support families in achieving optimal participation levels for their daughter with Rett syndrome, but strategies might relate to social networks, infrastructure, and community awareness. Organisations including disability services may therefore need to advocate for supportive and accessible environments for positive community participation experiences [39,40].

Daughter's whose mothers had a higher educational qualification were more likely to participate in an activity and frequently participate in activities. The importance of maternal education has been indicated in several studies finding that for children with an intellectual disability, their health and development as well as access to health facilities is predicted by

their mother's education [41]. Additionally, maternal education has been found to have the most powerful influence over their child's health and well-being when compared to other socio-economic predictors such as the father's education and parent's occupation [42]. Collectively these findings highlight the important role that maternal education can have on the development of children with an intellectual disability as well as a mother's empowerment in supporting a more comprehensive program of activities for their child with a disability

Another important finding was that girls and women whose families who were able to save money were more likely to participate in activities. This finding is consistent with previous studies of young adolescents with developmental disabilities suggesting that participation in social and recreational activities is predicted by the family's financial status [43]. These results of this study may suggest that a higher proportion of income is spent on meeting the medical and equipment needs of the child leaving less money to expend on discretionary community activities [43-45]. Therefore further planning and resourcing of cost-effective community activities and programs is needed for families and people with intellectual disabilities.

In this study, girls and women with Rett syndrome participated in a variety of activities. Recreational, physical/skill-based and social activities were often reported by families, whilst self-improvement activities were less frequently reported although some could argue that physical/skill-based (e.g. hydrotherapy) and social (e.g. shopping) activities may be regarded as self-improvement activities. It was expected that participation in recreational and social activities would be more common as they can accommodate for wheelchair use and increased severity of Rett syndrome [38,46]. For example, walking (recreational) was frequently

reported by majority of families as this activity could be undertaken with all levels of mobility. Physical/skill-based activities such as horse riding and swimming were also frequently reported as common activities in which the girls and women participated as they may help to build their skills as well as provide enjoyment. This study also found that there was no differences in that variety of activities between girls who were still at school and those who were post school, consistent with previous studies on children and adolescents with profound disabilities [13,25]. We can therefore conclude that many of the girls and women participated in a range of activities but challenges still remain in identifying the environment factors which further support accessible, affordable and meaningful participation in a more comprehensive range of activities.

Younger girls were more likely to participate in activities with a family member whilst older girls were more likely to participate with a carer. This is likely related to the higher proportion of older women living in a group home, increasing independence from the family and poorer physical health of parents as they age [47,48]. It is clear that care workers have a critical role in ensuring favourable quality of life for women with Rett syndrome. Several studies of adults with an intellectual disability have suggested that care workers influence the level of community participation for those for whom they care and are often unaware that their role includes facilitating activity participation [49]. This indicates the need for the resourcing of education and training programs for caring staff to enable a greater understanding of their role in facilitating participation in social and recreational activities as well as building strong and positive relationships for those they care for [50].

Families of children with severe disabilities are often faced with a difficult decision as to whether they should continue to care for their child, or place them in a community home [48].

When families do make the decision for their child to live out of home, they may experience a sense of guilt associated with no longer caring for their child [47]. However, living independently is an expected phase of transition [21]. For families who choose to care for their daughter with Rett syndrome at home, greater levels of support may be needed due to the complexity and severity of the disability [25,47]. For these families, supports such as respite services are important in alleviating stress [51].

The major strengths of this study were the population-based nature of the sample, the high response fraction and large sample size. The ICF framework [14] proved to be a valuable framework in identifying the factors affecting community participation whilst the CAPE model [33] provided a clear understanding on the variety of activities. This study was limited by our inability to describe the level of enjoyment and satisfaction experienced in activity for the girls. Parent proxy reporting may have contributed to parents over reporting or under reporting their daughter's participation in activities and there may have also been some degree of recall error with parents providing incorrect information. Lastly, our study was cross sectional and the results only reflect the 2009 sample. Longitudinal data is available in the database for future analysis.

Several other factors should be considered for future studies. Firstly, it would be important to gain further understanding of how the individual's current living situation affects their community participation. This could include if they live in a single parent family and levels of sibling involvement in activities. Secondly, qualitative research is needed to obtain further insight into the barriers and enablers of community participation.

Conclusion

In summary, Rett syndrome is a complex disability which can restrict community participation. The findings from this study have provided an insight into how impairment, personal and environmental factors can influence community participation for girls and women with Rett syndrome. By identifying the barriers to community participation, families, disability services and health professionals including occupational therapists can advocate and encourage the successful inclusion of not only girls and women with Rett syndrome, but also for all people with severe disabilities.

Key messages

- The majority of girls and women with Rett syndrome participated in recreational, physical/skill-based and social activities in the community.
- Frequency of participation was influenced by levels of mobility, community support and maternal education.
- As the girls grew older, they were more likely to participate with a carer and less likely to participate with family members.
- Further understanding of impairment, personal and environmental factors to provide meaningful, accessible and affordable community activities.

References

1. Laurvick C, De Klerk N, Bower C, Christodoulou J, Ravine D, Ellaway C, Williamson S, Leonard H. Rett syndrome in Australia: A review of the epidemiology. *The Journal of Pediatrics* 2006a;148(3):347-352.
2. Fehr S, Bebbington A, Nassar N, Downs J, Ronen GM, De Klerk N, Leonard H. Trends in the diagnosis of Rett syndrome in Australia. *Pediatric Research* 2011b;70(3):313-319.
3. Amir RE, Van den Veyver IB, Wan M, Tran CQ, Francke U, Zoghbi HY. Rett syndrome is caused by mutations in X-linked MECP2, encoding methyl-CpG-binding protein 2. *Nature Genetics* 1999;23(2):185.
4. Williamson SL, Christodoulou J. Rett syndrome: New clinical and molecular insights. *European Journal of Human Genetics* 2006;14(8):896-903.
5. Fehr S, Bebbington A, Ellaway C, Rowe P, Leonard H, Downs J. Altered attainment of developmental milestones influences the age of diagnosis of Rett syndrome. *Journal of Child Neurology* 2011a;26(8):980-987.
6. Leonard H, Fyfe S, Leonard S, Msall M. Functional status, medical impairments, and rehabilitation resources in 84 females with Rett syndrome: A snapshot across the world from the parental perspective. *Disability & Rehabilitation* 2001;23(3/4):107-117.
7. Crepeau EB, Cohn ES, Schell BA. Willard & Spackman's occupational therapy. Philadelphia, PA: Lippincott Williams and Wilkins; 2009.
8. Budruk M, Phillips R. Quality of life community indicators for parks, recreation and tourism management. London: Springer; 2011.
9. Specht J, King G, Brown E, Foris C. The importance of leisure in the lives of persons with congenital physical disabilities. *American Journal of Occupational Therapy* 2002;56(4):436-445.
10. Caldwell LL. Leisure and health: Why is leisure therapeutic? *British Journal of Guidance & Counselling* 2005;33(1):7-26.
11. Holder MD, Coleman B, Sehn ZL. The contribution of active and passive leisure to children's well-being. *Journal of Health Psychology* 2009;14(3):378-386.
12. Law M, Gillian K, King S, Kertoy M, Hurley P, Rosenbaum P, Young N, Hanna S. Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Developmental Medicine & Child Neurology* 2006;48:337-342.
13. Maes B, Vos P, Penne A. Analysis of daytime activities for children with profound intellectual and multiple disabilities in specific settings *The British Journal of Developmental Disabilities* 2010;56(111):123-136.
14. World Health Organization [WHO]. International classification of functioning, disability and health. Geneva, Switzerland: Author; 2005.
15. Michelsen SI, Flachs EM, Uldall P, Eriksen EL, McManus V, Parkes J, Parkinson KN, Thyen U, Arnaud C, Beckung E and others. Frequency of participation of 8-12-year-old children with cerebral palsy: A multi-centre cross-sectional European study. *European Journal of Paediatric Neurology* 2009;13(2):165-177.
16. King G, Law M, King S, Rosenbaum P, Kertoy MK, Young NL. A conceptual model of the factors affecting the recreational and leisure participation of children with disabilities. *Physical & Occupational Therapy in Pediatrics* 2003;23(1):63-90.

17. Dusseljee JCE, Rijken PM, Cardol M, Curfs LMG, Groenewegen PP. Participation in daytime activities among people with mild or moderate intellectual disability. *Journal of Intellectual Disability Research* 2011;55(1):4-18.
18. Majnemer A, Shevell M, Law M, Birnbaum R, Chilingaryan G, Rosenbaum P, Poulin C. Participation and enjoyment of leisure activities in school-aged children with cerebral palsy. *Developmental Medicine & Child Neurology* 2008;50(10):751-758.
19. Colver AF, Dickinson HO, Parkinson K, Arnaud C, Beckung E, Fauconnier J, Marcelli M. Access of children with cerebral palsy to the physical, social and attitudinal environment they need: A cross-sectional European study. *Disability and Rehabilitation* 2011;33(1):28-35.
20. Oates A, Bebbington A, Bourke J, Girdler S, Leonard H. Leisure participation for school-aged children with Down syndrome. *Disability & Rehabilitation* 2011;33(19/20):1880-1889.
21. Clarke M, Newton C, Petrides K, Griffiths T, Lysley A, Price K. An examination of relations between participation, communication and age in children with complex communication needs. *Augmentative and Alternative Communication* 2012;28(1):44-51.
22. Lishner DM, Richardson M, Levine P. Access to primary health care among persons with disabilities in rural areas: A summary of the literature. *The Journal of Rural Health* 1996;12:45-53.
23. Law M, Petrenchik T, King G, Hurley P. Perceived environmental barriers to recreational, community, and school participation for children and youth with physical disabilities. *Archives of Physical Medicine and Rehabilitation* 2007;88(12):1636-1642.
24. Leonard H, Thomson MR, Glasson EJ, Fyfe S, Leonard S, Bower C, Christodoulou J, Ellaway C. A population-based approach to the investigation of osteopenia in Rett syndrome. *Developmental Medicine & Child Neurology* 1999;41(5):323-328.
25. Neul JL, Kaufmann WE, Glaze DG, Christodoulou J, Clarke AJ, Bahi-Buisson N, Leonard H, Bailey ME, Schanen NC, Zappella M and others. Rett syndrome: Revised diagnostic criteria and nomenclature. *Annals of Neurology* 2010;68(6):944-950.
26. Mount RH, Charman T, Hastings RP, Reilly S, Cass H. The Rett syndrome behaviour questionnaire (RSBQ): Refining the behavioural phenotype of Rett syndrome. *Journal of Child Psychology and Psychiatry* 2002a;43(8):1099-1110.
27. Msall ME, DiGaudio K, Rogers BT, LaForest S, Catanzaro NL, Campbell J, Wilczenski F, Duffy LC. The functional independence measure for children (WeeFIM) : Conceptual basis and pilot use in children with developmental disabilities. *Clinical Pediatrics* 1994;33(7):421-430.
28. Dunst CJ, Jenkins V, Trivette JM. Enabling and empowering families: Principles and guidelines for practice. Cambridge, MA: Brookline Books; 1988.
29. Leet HE, Dunst CJ. Enabling and empowering families: Principles and guidelines for practice. Cambridge, MA: Brookline Books; 1988.
30. Australian Bureau of Statistics. Australian Standard Geographical Classification (ASGC). Canberra, ACT: Author; 2005. Report nr 1216.0.
31. Ware JE, Kosinski MA, Keller SD. A 12-item short-form health survey: Construction of scales and preliminary tests of reliability and validity. *Medical Care* 1996;34(3):220-233.
32. Australian Bureau of Statistics. Australian and New Zealand Standard Classification of Occupations (ANZSCO). Canberra, ACT: Author; 2006. Report nr 1220.0.

33. King GA, Law M, King S, Hurley P, Hanna S, Kertoy M, Rosenbaum P. Measuring childrens participation in recreation and leisure activities: Construct validation of the CAPE and PAC. *Child: Care, Health and Development* 2007;33(1):28-28.
34. Verdonshot MML, De Witte LP, Reichrath E, Buntinx WHE, Curfs LMG. Community participation of people with an intellectual disability: A review of empirical findings. *Journal of Intellectual Disability Research* 2009;53(4):303-318.
35. Jian L, Nagarajan L, de Klerk N, Ravine D, Christodoulou J, Leonard H. Seizures in Rett syndrome: An overview from a one-year calendar study. *European Journal of Paediatric Neurology* 2007;11(5):310-317.
36. Ager S, Fyfe S, Christodoulou J, Jacoby P, Schmitt L, Leonard H. Predictors of scoliosis in Rett syndrome. *Journal of Child Neurology* 2006;21(9):809-813.
37. Murphy NA, Carbone PS. Promoting the participation of children with disabilities in sports, recreation, and physical activities. *Pediatrics* 2008;121(5):1057-1061.
38. Urbanowicz A, Downs J, Bebbington A, Jacoby P, Girdler S, Leonard H. Use of equipment and respite services and caregiver health among Australian families living with Rett syndrome. *Research in Autism Spectrum Disorders* 2011;5(2):722-732.
39. Bigby C, Wiesel I. Encounter as a dimension of social inclusion for people with intellectual disability: Beyond and between community presence and participation. *Journal of Intellectual and Developmental Disability* 2011;36(4):263-267.
40. Abbott S, Mcconkey R. The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities* 2006;10(3):275-287.
41. Desai S, Alva S. Maternal education and child health: Is there a strong causal relationship? *Demography* 1998;35(1):71-81.
42. Hobcraft J. Women's education, child welfare and child survival: A review of the evidence. *Health Transition Review* 1993;3(2):159-175.
43. Van Naarden Braun K, Yeargin-Allsopp M, Lollar D. Factors associated with leisure activity among young adults with developmental disabilities. *Research in Developmental Disabilities* 2006;27(5):567-583.
44. Dyke P, Leonard H. The Australian Rett Syndrome Study Report 2006. Western Australia: Telethon Institute for Child Health Research; 2006.
45. Zurynski Y, Frith K, Leonard H, Elliott E. Rare childhood diseases: How should we respond? *Archives of Disease in Childhood* 2008;93(12):1071-1074.
46. Hagberg B, Hanefeld F, Percy A, Skjeldal O. An update on clinically applicable diagnostic criteria in Rett syndrome. *European Journal of Paediatric Neurology* 2002;6:293-297.
47. Heller T, Hsieh K, Rowitz L. Maternal and paternal caregiving of persons with mental retardation across the lifespan. *Family Relations* 1997;46(4):407-415.
48. Krauss MW, Seltzer MM, Jacobson HT. Adults with autism living at home or in non-family settings: Positive and negative aspects of residential status. *Journal of Intellectual Disability Research* 2005;49(2):111-124.
49. Perry J, Felce D. Factors associated with outcome in community group homes. *American Journal on Mental Retardation* 2005;110(2):121-135.
50. Johnson H, Douglas J, Bigby C, Iacono T. Social interaction with adults with severe intellectual disability: Having fun and hanging out. *Journal of Applied Research in Intellectual Disabilities* 2012;25(4):329-341.
51. Laurvick C, Msall M, Silburn S, Bower C, De Klerk N, Leonard H. Physical and mental health of mothers caring for a child with Rett syndrome. *Pediatrics* 2006b;118(4):1152-64.

Table I. Univariate relationships between impairment; personal and environmental factors and overall participation and frequency of activity participation.

<i>Categorical predictors</i>	Overall participation ^a (n = 175) (Activities / No activities)				Frequency of activities ^b (n = 214)			
	n (%)	OR	CI	p-value	n	IRR	CI	p-value
Mobility								
Dependent/Weight bear	76 (43.4%)	Ref.			92 (43.0%)	Ref.		
Severely restricted	32 (18.3%)	3.69	0.79-17.18	0.10	40 (18.7%)	1.41	0.99-2.02	0.06
Mildly restricted	67 (38.3%)	1.02	0.44-2.34	0.96	80 (38.2%)	1.21	0.89-1.64	0.22
Age (still at school)								
< 8	26 (14.9%)	Ref.			26 (23.0%)	Ref.		
8 < 13	41 (23.4)	1.07	0.33-3.45	0.91	42 (36.3%)	0.42	0.26-0.67	0.00
13 < still at school	46 (26.3%)	1.67	0.50-5.64	0.41	46 (40.7%)	0.52	0.33-0.83	0.01
Age (post school)	62 (35.4%)	2.03	0.62-6.57	0.24				
Parent home					62 (62.0%)	Ref.		
Group home					38 (38.0%)	0.99	0.69-1.43	0.97
Mother ANZSCO ^c								
Homemaker/Unemployed/Retired	77 (45.8%)	Ref.			77 (45.8%)	Ref.		
Clerk/Trades	55 (32.7%)	1.54	0.61-3.91	0.36	55 (32.7%)	1.05	0.73-1.50	0.81
Manager/professional	36 (21.4%)	2.10	0.65-6.80	0.22	36 (21.4%)	1.17	0.80-1.72	0.41
Father ANZSCO ^c								
Homemaker/Unemployed/Retired	22 (15.2%)	Ref.			22 (15.2%)	Ref.		
Clerk/Trades	61 (42.1%)	0.34	0.07-1.62	0.17	61 (42.1%)	1	0.75-1.81	0.49
Manager/professional	62 (42.8%)	0.79	0.15-4.10	0.78	62 (42.8%)	1	0.92-1.90	0.13
Maternal education ^c								
Primary or Some high school	49 (28.7%)	Ref.			49 (28.7%)	Ref.		
High school year 12	39 (22.8%)	0.85	0.31-2.37	0.76	39 (22.8%)	1.30	0.80-2.13	0.29
Vocational qualification	43 (25.2%)	1.12	0.40-3.16	0.83	43 (25.2%)	1.41	0.94-2.12	0.10
University degree	40 (23.4%)	4.87	1.00-23.71	0.05	40 (23.4%)	1.75	1.15-2.66	0.01
ARIA								
Major cities	122 (69.7%)	Ref.			147 (68.7%)	Ref.		
Inner regional	34 (19.4%)	0.97	0.36-2.64	0.95	44 (20.6%)	1.06	0.76-1.47	0.73
Very remote/ Remote/ Outer	19 (10.9%)	1.11	0.30-4.15	0.88	23 (10.8%)	1.17	0.82-1.67	0.38
Family spending ^c								
We cannot save	70 (42.9%)	Ref.			70 (42.9%)	Ref.		
Some left over each week but we spend it	8 (4.8%)	2.07	0.24-18.13	0.51	8 (4.8%)	0.81	0.48-1.39	0.45
We can save	85 (52.2%)	2.22	0.94-5.27	0.07	85 (52.2%)	1.27	0.91-1.77	0.15

Table I. (continued)

<i>Continuous Predictors</i>	Overall participation ^a (n = 175) (Activities / No activities)				Frequency of activities ^b (n = 214)			
	<i>Mean (SD)</i>	OR	CI	<i>p</i> -value	<i>Mean (SD)</i>	OR	CI	<i>p</i> -value
General Mood behaviours	7.7 (4.4)	1.03	0.94-1.13	0.55	7.9 (4.5)	1.00	0.97-1.03	0.96
Fear and Anxiety behaviours	4.0 (2.1)	1.09	0.91-1.32	0.35	3.9 (2.2)	0.99	0.94-1.05	0.72
Functional Independence	29.4 (14.4)	1.05	1.00-1.09	0.05	28.9 (14.0)	1.01	0.997-1.02	0.17
Parent Mental Health ^c	39.3 (10.3)	1.03	0.99-1.07	0.16	39.3 (10.3)	1.01	0.997-1.03	0.12
Parental Physical Health ^c	49.3 (8.8)	0.97	0.93-1.02	0.30	49.3 (8.8)	0.99	0.98-1.01	0.55
Community support ^c	2.6 (0.8)	1.59	0.90-2.80	0.11	2.6 (0.8)	1.22	1.03-1.44	0.02
Parent available time ^c	1.5 (0.5)	1.72	0.69-4.28	0.25	1.5 (0.5)	1.16	0.83-1.64	0.38

^a For overall participation, only girls and women living with parents were included in analysis; ^b For frequency of activities, all girls and women were included unless otherwise specified in the factors; ^c Only girls and women living with parents were included in analysis.

Table II. Univariate relationships between impairment, personal and environmental factors and variety of activities.

Variety of activities (n = 182)													
<i>Categorical predictors</i>	<i>n (%)</i>	Recreational (low 1-3 / high 4+)			Physical/Skill-based (low 1-3 / high 4+)			Social (low 1-3 / high 4+)			Self-improvement ^a		
		OR	CI	<i>p</i> -value	OR	CI	<i>p</i> -value	OR	CI	<i>p</i> -value	Low %	High %	<i>p</i> -value
Mobility													
Dependent/Weight bear	77	Ref.			Ref.			Ref.			0.00	100.00	
Severely restricted	38	1.24	0.54-2.85	0.62	2.42	0.78-7.46	0.13	2.46	0.81-7.49	0.11	12.50	87.50	
Mildly restricted	67	1.13	0.55-2.29	0.74	1.57	0.67-3.65	0.30	1.33	0.56-3.15	0.52	10.00	90.00	0.31
Age (still at school)													
< 8	20	Ref.			Ref.			Ref.			50.00	50.00	
8 < 13	32	1.53	0.46-5.04	0.48	1.46	0.39-5.40	0.57	0.41	0.07-2.41	0.32	0.00	100.00	
13 < still at school	39	1.48	0.48-4.53	0.49	2.25	0.59-8.58	0.24	0.69	0.12-3.94	0.67	0.00	100.00	0.17
Age (post school)													
Parent home	54	Ref.			Ref.			Ref.			14.29	85.71	
Group home/Hostel	37	1.52	0.59-3.89	0.38	1.32	0.41-4.28	0.65	1.28	0.43-3.86	0.66	0.00	100.00	0.35
Mother ANZSCO ^c													
Homemaker/Unemployed/Retired	61	Ref.			Ref.			Ref.			0.00	100.00	
Clerk/Trades	47	2.26	0.97-5.24	0.06	1.98	0.75-5.26	0.17	1.82	0.65-5.11	0.26	10.00	90.00	
Manager/professional	32	1.20	0.49-2.98	0.69	2.29	0.74-7.08	0.15	1.30	0.41-4.15	0.66	0.00	100.00	1.00
Father ANZSCO ^c													
Homemaker/Unemployed/Retired	20	Ref.			Ref.			Ref.			0.00	100.00	
Clerk/Trades	47	1.04	0.35-3.11	0.94	0.59	0.16-2.12	0.42	0.77	0.19-3.09	0.71	0.00	100.00	
Manager/professional	55	0.95	0.33-2.73	0.93	0.94	0.27-3.26	0.92	0.82	0.22-3.10	0.77	11.11	88.89	1.00
Maternal education ^c													
Primary or Some high school	39	Ref.			Ref.			Ref.			16.67	83.33	
High school year 12	30	3.33	1.16-9.61	0.03	1.35	0.40-4.57	0.63	2.88	0.80-10.35	0.11	0.00	100.00	
Vocational qualification	35	2.11	0.79-5.65	0.14	2.02	0.60-6.83	0.26	1.93	0.58-6.40	0.28	0.00	100.00	
University degree	38	2.10	0.81-5.40	0.13	2.19	0.68-7.04	0.19	2.96	0.88-9.95	0.08	0.00	100.00	0.38

Table II. (continued)

	Recreational				Physical/Skill-based			Social			Self-improvement ^a		
	(low 1-3 / high 4+)				(low 1-3 / high 4+)			(low 1-3 / high 4+)					
<i>Categorical predictors</i>	<i>n (%)</i>	OR	CI	<i>p</i> -value	OR	CI	<i>p</i> -value	OR	CI	<i>p</i> -value	Low %	High %	<i>p</i> -value
ARIA													
Major cities	134	Ref.			Ref.			Ref.			5.88	94.12	
Inner regional	38	1.07	0.49-2.5	0.87	0.85	0.32-2.23	0.74	1.30	0.49-3.43	0.60	8.33	91.67	
Very remote/ Remote/ Outer	20	1.21	0.42-3.51	0.72	0.64	0.20-1.98	0.43	1.59	0.41-6.17	0.50	0.00	100.00	1.00
Family spending ^c													
We cannot save	54	Ref.			Ref.			Ref.			12.50	87.50	
Some left over each week but we spend it	7	1.77	0.30-10.57	0.53	1.63	0.15-17.24	0.69	^b			0.00	100.00	
We can save	75	1.73	0.82-3.65	0.15	1.39	0.563-4.8	0.48	1.76	0.69-4.51	0.24	0.00	100.00	0.48
<i>Continuous Predictors</i>	Mean (SD)										OR	CI	<i>p</i> -value
General Mood behaviours	8.0 (4.5)	0.95	0.89-1.02	0.19	0.97	0.89-1.06	0.46	1.02	0.93-1.13	0.67	0.64	0.39-1.06	0.08
Fear and Anxiety behaviours	4.0 (2.1)	0.98	0.85-1.14	0.80	0.99	0.84-1.18	0.95	1.09	0.89-1.33	0.39	0.64	0.28-1.50	0.31
Functional independence	29.6 (14.6)	1.00	0.98-1.02	0.91	1.01	0.98-1.04	0.60	1.00	0.97-1.04	0.84	1.01	0.89-1.14	0.94
Parent Mental Health ^c	39.8 (10.1)	1.00	0.97-1.04	0.98	1.03	0.98-1.08	0.23	0.99	0.94-1.03	0.62	1.00	0.81-1.24	0.97
Parental Physical Health ^c	40.0 (9.1)	1.00	0.97-1.04	0.91	0.99	0.94-1.04	0.83	1.00	0.95-1.06	0.87	1.20	0.89-1.62	0.23
Community support ^c	2.6 (0.8)	1.20	0.76-1.88	0.44	0.86	0.49-1.48	0.58	1.34	0.76-2.35	0.31	1.80	0.08-40.08	0.71
Parent available time ^c	1.5 (0.5)	1.17	0.55-2.49	0.69	0.91	0.35-2.38	0.84	1.07	0.39-2.95	0.89	1.03	0.01-98.87	0.99

^a Due to the small sample in self-improvement activities ($n=32$), a Fisher's exact test was used for the analysis instead of logistic regression; ^b Due to the small sample ($n=7$), unable to analyse this category with logistic regression; ^c Only girls and women living with parents were included in analysis.

Table III. Univariate relationships between impairment, personal and environmental factors and involvement with family and carer.

<i>Categorical predictors</i>	Participates with in the activity (<i>n</i> =182)						
	(Carer / No Carer)				(Family / No family)		
	<i>n</i> (%)	OR	CI	<i>p</i> -value	OR	CI	<i>p</i> -value
Mobility							
Dependent/Weight bear	77 (42.3%)	Ref.					
Severely restricted	38 (20.9%)	0.92	0.48-1.78	0.80	1.07	0.58-1.98	0.83
Mildly restricted	67 (36.8%)	0.93	0.53-1.63	0.79	1.12	0.67-1.88	0.67
Age (still at school)							
< 8	20 (22.0%)	Ref.			Ref.		
8 < 13	32 (25.2%)	1.49	0.55-3.98	0.43	0.63	0.23-1.68	0.36
13 < still at school	39 (42.9%)	2.04	0.79-5.26	0.14	0.57	0.22-1.49	0.25
Age (post school)							
Parent home	54 (59.3%)	Ref.			Ref.		
Group home	37 (40.7%)	3.62	1.43-9.19	0.01	0.32	0.15-0.70	0.00
Mother ANZSCO ^a							
Homemaker/Unemployed/Retired	61 (43.6%)	Ref.			Ref.		
Clerk/Trades	47 (33.6%)	1.26	0.66-2.41	0.49	0.87	0.47-1.60	0.65
Manager/professional	32 (22.9%)	1.67	0.82-3.40	0.16	0.64	0.34-1.20	0.16
Father ANZSCO ^a							
Homemaker/Unemployed/Retired	20 (16.4%)	Ref.			Ref.		
Clerk/Trades	47 (38.5%)	0.85	0.35-2.02	0.71	0.96	0.42-2.19	0.92
Manager/professional	55 (45.1%)	0.92	0.40-2.09	0.83	1.03	0.49-2.20	0.93
Maternal education ^a							
Primary or Some high school	39 (27.5%)	Ref.			Ref.		
High school year 12	30 (21.1%)	1.57	0.69-3.59	0.28	0.92	0.43-1.97	0.83
Vocational qualification	35 (24.7%)	0.83	0.38-1.82	0.64	1.14	0.55-2.36	0.73
University degree	38 (26.8%)	1.05	0.49-2.27	0.90	0.90	0.45-1.83	0.78
ARIA							
Major cities	134 (68.1%)	Ref.			Ref.		
Inner regional	38 (20.9%)	0.96	0.51-1.79	0.89	1.27	0.69-2.33	0.45
Very remote/ Remote/ Outer	20 (11.0%)	1.42	0.59-3.41	0.44	0.86	0.41-1.81	0.69
Family spending ^a							
We cannot save	54 (39.7%)	Ref.			Ref.		
Some left over each week but we spend it	7 (5.2%)	1.03	0.29-3.67	0.96	1.09	0.29-4.13	0.90
We can save	75 (55.2%)	1.28	0.71-2.32	0.41	0.93	0.54-1.61	0.79

Table III. (continued)

<i>Continuous Predictors</i>	(Carer / No Carer)				(Family / No family)		
	<i>n (%)</i>	OR	CI	<i>p</i> -value	OR	CI	<i>p</i> -value
General Mood behaviours	8.0 (4.5)	1.01	0.95-1.07	0.71	0.99	0.94-1.04	0.70
Fear and Anxiety behaviours	4.0 (2.1)	0.93	0.83-1.05	0.24	1.06	0.95-1.18	0.31
Functional independence	29.6 (14.6)	1.01	0.99-1.02	0.58	0.99	0.98-1.01	0.54
Parent Mental Health ^a	39.8 (10.1)	1.01	0.99-1.04	0.31	0.99	0.97-1.02	0.51
Parental Physical Health ^a	40.0 (9.1)	0.99	0.96-1.03	0.70	1.00	0.97-1.03	0.87
Community support ^a	2.6 (0.8)	0.89	0.62-1.27	0.52	1.13	0.82-1.54	0.45
Parent available time ^a	1.5 (0.5)	0.93	0.50-1.73	0.82	1.08	0.60-1.95	0.79

^a Only girls and women living with parents were included in analysis.

Guidelines for Contributions by Authors

For research report only

Journal of Disability and Rehabilitation

Journal guidelines

Disability and Rehabilitation

Instructions for Authors

Disability and Rehabilitation is an international interdisciplinary journal and particularly welcomes contributions from a wide range of professional groups, including medical practitioners, occupational therapists, physiotherapists, speech and language therapists, clinical psychologists and those involved in nursing, education and engineering.

Disability and Rehabilitation is organised into sections: Reviews; Research Papers; Case Studies; Perspectives on Rehabilitation; reports on Rehabilitation in Practice, Education and Training and Correspondence.

Special Issues and specific sections on contemporary themes of interest to the Journal's readership are published. Please contact the Editor for more information.

Submissions and Peer-Review

All submissions should be made online at *Disability and Rehabilitation*'s ScholarOne Manuscripts site: <http://mc.manuscriptcentral.com/dandr>.

Authors are given the option to remain anonymous during the peer-review process. Authors will be able to indicate whether their paper is „Anonymous“ or „Not Anonymous“ during manuscript submission, and should pay particular attention to the below:

Authors who wish to remain anonymous should prepare a complete text with information identifying the author(s) removed. This should be uploaded as the „Main Document“ and will be sent to the referees. Any acknowledgements and the Declaration of Interest statement must be included but should be worded mindful that these sections will be made available to referees.

Authors who wish to be identified should include the name(s) and affiliation(s) of author(s) on the first page of the manuscript. The complete text should be uploaded as the „Main Document“.

All submissions should include a separate title page that contains contact information for the authors(s). This should be uploaded as a „Title Page“ and will not be sent to referees.

If a paper is deemed to be acceptable for publication pending minor revision, the author(s) names may be disclosed to the referees when the Editor's decision is made, irrespective of whether the authors names(s) were included as part of the original submission. Every effort will be made to keep the author(s) name(s) anonymous, if required, should the paper require extensive revision and further peer-review. If authors wish to remain anonymous throughout the second round of peer-review, they are reminded not to include identifying information in the „Authors' Response“ section during the upload of their revised paper.

Every paper that is revised and resubmitted must clearly indicate the parts of the manuscript that contain amendments, by highlighting the revised text in a different colour or by using „Track Changes“ (for minor revisions).

Please contact the Editor if you require more information.

Systematic Reviews should be submitted as a „Review“ and Narrative Reviews should be submitted as „Perspectives in Rehabilitation“. All Systematic Reviews will be automatically submitted for the annual Best Review Paper competition.

Education and Training

This is a new section for the journal. It will publish papers relating to the education and professional training of those working in the field of rehabilitation. Papers are encouraged which develop innovative approaches to this process and provide multi-disciplinary and international comparisons for those working in the field. Through this new section it is intended to contribute towards the development of education and training within these professional groupings.

Papers should be submitted with any tables, figures, or photographs, all of which should be of high quality suitable for reproduction. Submissions should be in English presented in double line spacing.

Submissions should include, where appropriate, a formal statement that ethical consent for the work to be carried out has been given. Photographs of patients should be avoided, but if essential, patients' consent in writing must accompany manuscript. It is not sufficient to mask identity by covering the patients' eyes.

Word Limit

There is no stated word limit to papers submitted to *Disability and Rehabilitation*. It should however be noted that space is at a premium and therefore succinct and well-constructed papers are more likely to be reviewed positively. However, the key to evaluating a paper will be the quality of the work along with the methodology adopted particularly for qualitative studies which do tend to be longer.

Disability and Rehabilitation considers all manuscripts at the Editor's discretion; the Editor's decision is final. Please see below for information on the Journal's Appeal Procedure.

Disability and Rehabilitation considers all manuscripts on the strict condition that they are the property (copyright) of the submitting author(s), have been submitted only to *Disability and Rehabilitation*, that they have not been published already, nor are they under consideration for publication, nor in press elsewhere. Authors who fail to adhere to this condition will be charged all costs which *Disability and Rehabilitation* incurs, and their papers will not be published. Copyright will be transferred to *Disability and Rehabilitation* and Informa UK Ltd., if the paper is accepted.

IMPLICATIONS FOR REHABILITATION

A feature of the Journal is a boxed insert on „Implications for Rehabilitation“. This box should include between two to four main bullet points drawing out the implications for rehabilitation for your paper. **All papers including reviews, research, rehabilitation in practice, perspectives on rehabilitation, case studies and a new section on education and training for rehabilitation professionals must include this feature.** This should be uploaded as a separate document through Manuscript Central as a single side of A4 during submission.

Included below are examples. If you have any questions, please contact the Editor.

Example 1: Leprosy

- Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
- Reconstructive surgery is a technique available to this group.
- In a relatively small sample this study shows participation and social functioning improved after surgery.

Example 2: Multiple Sclerosis

- Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
- People with MS have complex reasons for choosing to exercise or not.
- Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.

Example 3: Community Based Rehabilitation

- Community Based Rehabilitation (CBR) is a Western concept that may not readily fit other cultures.
- CBR needs to be „owned“ by those involved and subject to re-interpretation to be effective in other cultures.

Manuscript Preparation

In writing your paper, you are encouraged to review articles in the area you are addressing which have been previously published in the Journal and where you feel appropriate, to reference them. This will enhance context, coherence, and continuity for our readers.

File preparation and types

Manuscripts are preferred in Microsoft Word format (.doc files). Documents must be double-spaced, with margins of one inch on all sides. Tables and figures should not appear in the main text, but should be uploaded as separate files and designated with the appropriate file type upon submission. These should be submitted as "Image" files during submission. References should be given in Council of Science Editors (CSE) Citation & Sequence format (see References section for examples).

Structure of Paper

Manuscripts should be compiled in the following order: title page; abstract; main text; acknowledgments; Declaration of Interest statement; appendices (as appropriate); references; tables with captions (uploaded as separate files); figures with captions (uploaded as separate files).

An introductory section should state the purpose of the paper and give a brief account of previous work. New techniques and modifications should be described concisely but in sufficient detail to permit their evaluation; standard methods should simply be referenced. Experimental results should be presented in the most appropriate form, with sufficient explanation to assist their interpretation; their discussion should form a distinct section. Extensive tabulations will not be accepted unless their inclusion is essential.

Title Page

A title page should be provided comprising the manuscript title plus the full names and affiliations of all authors involved in the preparation of the manuscript. One author should be clearly designated as the corresponding author and full contact information, including phone number and email address, provided for this person. Keywords that are not in the title should also be included on the title page. The keywords will assist indexers in cross indexing the article. The title page should be uploaded separately to the main manuscript and designated as "title page" on ScholarOne Manuscripts. This will not get sent to referees.

Abstracts

Structured abstracts are required for all papers, and should be submitted as detailed below, following the title page, preceding the main text.

Purpose State the main aims and objectives of the paper.

Method Describe the design, and methodological procedures adopted.

Results Present the main results.

Conclusions State the conclusions that have been drawn and their relevance to the study of disability and rehabilitation.

The abstract should not exceed 200 words.

Nomenclature and Units

All abbreviations and units should conform to SI practice. Drugs should be referred to by generic names; trade names of substances, their sources, and details of manufacturers of scientific instruments should be given only if the information is important to the evaluation of the experimental data.

Copyright Permission

Contributors are required to secure permission for the reproduction of any figure, table, or extensive (more than fifty word) extract from the text, from a source which is copyrighted - or owned - by a party other than Informa UK Ltd or the contributor.

This applies both to direct reproduction or 'derivative reproduction' - when the contributor has created a new figure or table which derives substantially from a copyrighted source.

Code of Experimental Ethics and Practice

Contributors are required to follow the procedures in force in their countries which govern the ethics of work done with human or animal subjects. The Code of Ethics of the World Medical Association (Declaration of Helsinki) represents a minimal requirement.

Tables, figures and illustrations

The same data should not be reproduced in both tables and figures. The usual statistical conventions should be used: a value written 10.0 ± 0.25 indicates the estimate for a statistic (e.g. a mean) followed by its standard error. A mean with an estimate of the standard deviation will be written 10.0 SD 2.65.

Contributors reporting ages of subjects should specify carefully the age groupings: a group of children of ages e.g. 4.0 to 4.99 years may be designated 4 +; a group aged 3.50 to 4.49 years 4 ± and a group all precisely 4.0 years, 4.0.

Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. 'As seen in table [or figure] 1 ...' (not Tab., fig. or Fig).

The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript:

Insert table 2 about here

Each table and/or figure must have a title that explains its purpose without reference to the text. The filename for the tables and/or figures should be descriptive of the graphic, e.g. table 1, figure 2a.

Tables

Tables should be used only when they can present information more efficiently than running text.

Care should be taken to avoid any arrangement that unduly increases the depth of a table, and the column heads should be made as brief as possible, using abbreviations liberally. Lines of data should not be numbered nor run numbers given unless those numbers are needed for reference in the text.

Columns should not contain only one or two entries, nor should the same entry be repeated numerous times consecutively. Tables should be grouped at the end of the manuscript on uploaded separately to the main body of the text.

Figures and illustrations

Figures must be uploaded separately and not embedded in the text. Avoid the use of colour and tints for purely aesthetic reasons. Figures should be produced as near to the finished size as possible.

Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC). All files must be 300 dpi or higher.

Please note that it is in the author's interest to provide the highest quality figure format possible.

Please do not hesitate to contact our Production Department if you have any queries.

Acknowledgments and Declaration of Interest sections

Acknowledgments and Declaration of interest sections are different, and each has a specific purpose.

The Acknowledgments section details special thanks, personal assistance, and dedications.

Contributions from individuals who do not qualify for authorship should also be acknowledged here.

Declarations of interest, however, refer to statements of financial support and/or statements of potential conflict of interest. Within this section also belongs disclosure of scientific writing assistance (use of an agency or agency/ freelance writer), grant support and numbers, and statements of employment, if applicable.

Acknowledgments section

Any acknowledgments authors wish to make should be included in a separate headed section at the end of the manuscript preceding any appendices, and before the references section. Please do not incorporate acknowledgments into notes or biographical notes.

Declaration of Interest section

All declarations of interest must be outlined under the subheading "Declaration of interest". If authors have no declarations of interest to report, this must be explicitly stated. The suggested, but not mandatory, wording in such an instance is: *The authors report no declarations of interest.* When submitting a paper via ScholarOne Manuscripts, the "Declaration of interest" field is compulsory (authors must either state the disclosures or report that there are none). If this section is left empty authors will not be able to progress with the submission.

Please note: for NIH/Wellcome-funded papers, the grant number(s) must be included in the Declaration of Interest statement.

Click here to view our full Declaration of Interest Policy.

Mathematics

Click for more information on the presentation of mathematical text.

References

References should follow the Council of Science Editors (CSE) Citation & Sequence format. Only works actually cited in the text should be included in the references. Indicate in the text with Arabic numbers inside square brackets. Spelling in the reference list should follow the original. References should then be listed in numerical order at the end of the article. Further examples and information can be found in The CSE Manual for Authors, Editors, and Publishers, Seventh Edition. Periodical abbreviations should follow the style given by Index Medicus.

Examples are provided as follows:

Journal article: [1] Steiner U, Klein J, Eiser E, Budkowski A, Fethers LJ. Complete wetting from polymer mixtures. *Science* 1992;258:1122-9.

Book chapter: [2] Kuret JA, Murad F. Adenohypophyseal hormones and related substances. In: Gilman AG, Rall TW, Nies AS, Taylor P, editors. *The pharmacological basis of therapeutics*. 8th ed. New York: Pergamon; 1990. p 1334-60.

Conference proceedings: [3] Irvin AD, Cunningham MP, Young AS, editors. *Advances in the control of Theileriosis*. International Conference held at the International Laboratory for Research on Animal Diseases; 1981 Feb 9-13; Nairobi. Boston: Martinus Nijhoff Publishers; 1981. 427 p.

Dissertations or Thesis: [4] Mangie ED. *A comparative study of the perceptions of illness in New Kingdom Egypt and Mesopotamia of the early first millennium* [dissertation]. Akron (OH): University of Akron; 1991. 160 p. Available from: University Microfilms, Ann Arbor MI; AAG9203425.

Journal article on internet: [5] De Guise E, Leblanc J, Dagher J, Lamoureux J, Jishi A, Maleki M, Marcoux J, Feyz M. 2009. Early outcome in patients with traumatic brain injury, pre-injury alcohol abuse and intoxication at time of injury. *Brain Injury* 23(11):853-865.
<http://www.informaworld.com/10.1080/02699050903283221>. Accessed 2009 Oct 06

Webpage: [6] *British Medical Journal* [Internet]. Stanford, CA: Stanford Univ; 2004 July 10 - [cited 2004 Aug 12]; Available from: <http://bmj.bmjournals.com>

Internet databases: [7] *Prevention News Update Database* [Internet]. Rockville (MD): Centers for Disease Control and Prevention (US), National Prevention Information Network. 1988 Jun - [cited 2001 Apr 12]. Available from: <http://www.cdcnpi.org/>

APPEAL PROCEDURE

Disability and Rehabilitation and Disability and Rehabilitation: Assistive Technology

The Editors of both Journals will respond to appeals from Authors relating to papers which have been rejected.

The Author(s) should email the Editor outlining the concerns and making a case for why their paper should not have been rejected. The Editor will undertake one of two courses of action:

1: The Editor Accepts the Appeal

- I. In this case the Editor will secure a further review making available confidentially the relevant information for the reviewer
- II. The Editor on receiving the review will either accept the appeal and therefore invite a resubmission for further review; or reject the appeal and no further action will be taken.
- III. If an appeal is rejected there will be no further right of appeal within the jurisdiction of the Journal.

2: The Editor does not uphold the Appeal

- I. If the Editor does not accept the appeal and is not prepared to secure further review the decision will be referred to the Editor of the relevant affiliated Journal for independent consideration. In the case of *Disability and Rehabilitation*, the Editor of *Disability and Rehabilitation: Assistive Technology* will be contacted, and if an appeal is not upheld by the Editor of *Disability and Rehabilitation: Assistive Technology*, the Editor of *Disability and Rehabilitation* will be consulted.
- II. The Editor will either confirm the decision or recommend that a further review be obtained.
- III. Therefore, if both Editors agree that the appeal should not be upheld there will be no further right of appeal within the jurisdiction of the Journal.

Dave Muller, Editor in Chief, *Disability and Rehabilitation*

Marcia Scherer, Editor, *Disability and Rehabilitation: Assistive Technology*